



# Unheard Voices: interviews with deafened people

Kathryn Wharton  
Interviewed by Stephen Beal

British Library ref. C1345/24

## IMPORTANT

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## Interview Summary Sheet

**Ref no:** C1345/24

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

**Interviewee's surname:** Wharton

**Title:**

**Interviewee's forename:** Kathryn

**Sex:** Female

**Occupation:**

**Date and place of birth:** 1961

**Date(s) of recording:** 14<sup>th</sup> March 2009

**Location of interview:** The City Inn Hotel, Bristol

**Name of interviewer:** Stephen Beal

**Speech to Text reporter:** Mirella Fox

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

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

**Total no. of tracks:** 1

**Mono or stereo:** stereo

**Total Duration:** 1 hr. 22 min.

**Additional material:**

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**Interviewer's comments:**

**[Track 1]**

*This is Steven Beal; I am interviewing Kathryn Wharton on Saturday 14<sup>th</sup> March 2009 for the Unheard Voices Project in Bristol. The Speech-To-Text reporter is Mirella Fox. Thank you for coming and I hope you had a nice trip down.*

Yes I did.

*And it was a long drive for you, both.*

Well for my husband, I dosed most of the way, so.

*Okay. Could you please give me your full name including your maiden name?*

Our middle name as well? So Kathryn Louise Wharton, my maiden name is Skelly, S-K-E-L-L-Y.

*And could you give me your date of birth?*

26/04/61.

*And do you have, did you have an occupation or are you –*

I was in retail, but I haven't worked for a couple of years now.

*Good. And could you give me your mother and father's occupation please?*

My dad's a retired plumber, and my mum was always a housewife.

*When you had, remember your first house or accommodation you lived in with your parents, do you know, can you remember much about it?*

Yes, yes.

*Was it a house, a flat?*

We lived in Cardiff, it was a house, a big house. Do you want me to just sort of talk about it?

*Just summarise on what you had please.*

A big house, 4 bedrooms. I have two brothers, so and my Nan used to live with us, and -- I don't know what else do I say?

*Was there a reason why your Nan lived with you?*

Just because she was old, got older and mum was the one who she was close to, so.

*Were your parents Welsh?*

Yes they are Welsh yes.

*And your father was a plumber, did he enjoy his work?*

I think sometimes yes, and sometimes no.

*Like all of us.*

He actually wanted to be a carpenter. This is what he has always told us but leaving school at 14 back then he couldn't get an apprenticeship to be a carpenter and he ended up as a plumber instead.

*And did your mother work?*

She has worked yes, she used to work in a place called Companies House in Cardiff as a paper keeper but she was mainly at home with us. And my Nan.

*Okay. Was it a happy childhood?*

Yes very.

*Obviously up in Wales you have beautiful scenery; did you manage to travel round Wales as child?*

Yes a bit. We used to go to North Wales normally for our holidays, but which is beautiful up there. But I haven't been up there for a long time now, but I come back to Cardiff quite often to see friends and some family still living there.

[03:25]

*Now up until the age of 11 when I notice you started having a hearing problem, were you quite a healthy child up until?*

Yes, absolutely fine. I don't remember having any problems with anything. Just noticing at roundabout the age of ten or 11, that I couldn't hear very well and my left ear, but I just compensated entirely with my right and it never bothered me.

*So before you have problems did the school notice any problems with your hearing at all?*

No, because I never actually brought any attention to it at all. I do not think I even told my parents because I just sort of had my writing was fine and I it didn't bother me, didn't stop me doing anything. I just found I used the phone it was better on the my right ear than my left, I remember that.

*Did your parents have any health problems?*

No, no.

*Grandparents do you know of?*

Only thing my dad can remember is when his father got into his 80s, he started to have some balance problems, but it was probably an age thing. But there has never been any signs, touch wood, of anybody in my family having Meniere's disease.

*No. I will come on to the Meniere's a bit later, but when you in your childhood, did you have any other health problems at all apart from the Meniere's?*

No not that I remember at all, no.

*You said you had a brother?*

Two brothers.

*Did they have any hearing problems?*

None at all, they are fine.

*They have had quite a healthy childhood?*

Yes fine yes.

[05:04]

*Okay. So, when you started infant primary school did you enjoy that school?*

I enjoyed primary school, yes I did, I remember.

*And were you a sporty person?*

Only in like gymnastics, and I was mad about horses.

*Plenty of room in Wales for horses.*

Yes.

*And your parents were they sporty at all?*

My mother –

*Did she have hobbies?*

My mother was a very good runner, even though she was very short, she was a good runner but not really, no.

*And your parents, they're retired now?*

Yes.

*And they're still quite healthy?*

Touch wood, dad is 80 now and mum is 78, but yes they are absolutely brilliant.

*Do they still live in Cardiff?*

They live next door to me in Cornwall.

*So you get to see them quite a bit*

Yes, I do.

*Okay. You said you liked horses, and did you ride horses when you were younger?*

Yes I did.

*Did you own a horse?*

I didn't actually own one, no. I used to borrow, borrow beach ponies believe it or not from Barry Island Beach, and I used to have them for the whole winter months me and my friends and we would sort of think that was like our own pony. We just had to look after them and we rode them as much as we wanted.



*Yes. And has that extended in your life, do you still ride horses?*

Not now, no.

[06:45]

*Okay. Okay. So you started you had a problem, you said, possibly when you were using the telephone. What did you think then because you were only young?*

I was very young yes.

*Did you confide in your parents?*

I don't remember telling them that I had noticed my left ear wasn't as good as my right hearing wise, because I think at that stage my right was obviously completely normal still and my left was starting to go down, so I didn't see it as a problem then.

*And you say you had Meniere's disease, obviously you didn't know then what Meniere's was?*

No, never heard of it.

*So, being 11 years old to come up to 12, did you attend doctors, with the hearing problem?*

Yes, when I was 12 I think I was about 12 and I remember I actually remember the first sort of attack I had and I remember to this day.

*Could you explain what happened to you?*

Yes, I actually, it is unbelievable, but I remember it being a Sunday evening, because I can remember being in our front room and saying to my mum, and I don't feel very well, I feel really strange and how I explained it, and it wasn't a vertigo attack; it was just a really strange sensation in my head. And I remember her saying, go and sit on the sofa next to your dad. And I remember doing it and then after a while it obviously passed off. But then from then on, I started to get these strange feelings that eventually developed into actual dizzy attacks

that got worse. And that kind of went on between the age of 12, and 16, and obviously mum took me to the doctors, and for a long time we were fobbed off with it's only her age, she will grow out of it. We had this for about this went on for about, I can't, 18 months or so and she -- until in the end my mother got really angry and said, I want to be referred to somebody else because this isn't her age, it is not normal what she is experiencing. Because they got worse, the attacks were getting worse.

And by then my I knew my hearing was bad in that ear and then I got referred to an ENT specialist, in Cardiff.

*At what sort of age were you when you got referred to an ENT specialist?*

I think by the time that happened I must have been roundabout 15 I think, because it dragged on.

*Okay. So, before we come to that, obviously being young, you had a good school friend base?*

Yes.

*Did your friends understand what was happening to you?*

Not back then, no.

*Did you have attacks in front of your friends?*

Yes in this school.

*How, were the teachers aware you had these problems?*

No, what I tended to do back then I was at that, I think at that age I was like I went to the comprehensive at 11. So it started when I would have been about the second year there. I was actually embarrassed and I didn't like to tell people at first because I didn't know what was happening to me. I couldn't understand why I was getting these attacks.

So I actually remember sitting through some lessons having an attack and not saying a word to anybody, which I look back now and find amazing because I do not know how I did it. I felt that bad, because I didn't know how to describe what I was feeling. But a few times I did and I was taken down to the school nurse, but again at that stage I didn't know what was happening to me and I couldn't understand why I was getting these attacks.

*Did was the school nurse helpful?*

I remember just laying down, waiting for it to pass off. But I don't suppose she had a clue really what was happening to me.

*No. And what about your friends, were they concerned?*

Some, yes, I suppose a couple of my close friends would have been, but again they didn't know why I was going, because they were they were all fine, and this is what my argument was with the doctor. All my friends aren't getting these attacks, if it's an age thing, why am I getting them, nobody else I know is. And I mean me and my family knew that it wasn't just an age thing. It was definitely something else.

*And do you think it affected your school work?*

Yes, and it affected the whole of my comprehensive years. Because my confidence went bang. Because I was frightened all the time of having one of these attacks everywhere I went.

*Apart from the comprehensive, what about emotions, were you emotional because of it?*

Probably, yes.

*Did, if you did PE, things like that did that affect it?*

Yes, because I love gymnastics. I remember I used to go to gymnastic classes and then one of the attacks started. I couldn't because obviously I couldn't do the flips and that kind of

thing because my balance wasn't good then, so it did affect that and that was the one thing I really did like.

[12:00]

*And so, you eventually got to see so you were on any medication at that time?*

Nothing at that stage no. I probably, to think about it, did get referred earlier than 15. I must have been, have got referred when I was about 14 because I just had loads and loads of tests, continuous tests that went on for I think I had three years of tests until eventually they decided in Cardiff I had a brain tumour and I remember sitting - I was 16 at that time actually. It went on until I was 16, having the test and I remember sitting in a tiny little room with my dad and he had a skull in my hand. I can remember it. It was Mr. Griffith and he said, we are 99.9 per cent sure she has a brain tumour, it is very deep. We can't cope with it here, in this hospital. And he, my dad then went as white as the wall. That's what I remember clearly. The colour just drained out of my dad's face.

*How did you feel when he said that?*

To be honest, I don't think I took it in. I think I sat there a bit numb and wasn't really taking in what this man was saying, because he was saying we are going to have to destroy this, destroy this, destroy that, to get to this tumour and you know it was like, I it was like I think I disconnected myself; like he is talking about somebody else and not me.

Anyway, I got referred to Andrew Morrison in London, who was a leading specialist in Meniere's, in neurological, at that time, didn't know Meniere's then, and it was thanks to him after a week in the London hospital of tests they discovered it wasn't a tumour and it was actually something called Meniere's disease. Which is obviously a huge relief, huge relief, because being a brain tumour I didn't know what was going to happen, if it had been you know it would have been much worse, but...

*So how did you feel in London away from Cardiff? Were you nervous?*

It was scary because it was an old hospital, the Whitechapel, the London hospital in Whitechapel. They were ever so nice there. I remember I was 16 at the time, and I just

remember one particular, there was a girl in the bed opposite me. She was 21, ever so pretty, long blonde hair, and she had an inoperable brain tumour and that is when it hit me that that could have been me and I always remember that. Because she had she's probably not here any more, I presume, because they couldn't do anything for her and I remember thinking, my God, if I had the brain tumour that could have been me. But now I have something called Meniere's disease, so...

*So, when the specialist said to you and your parents, you've got Meniere's disease did you think, my God what is that?*

Yes, never heard of it, yes. Not a clue what it was.

*No, and by this time your hearing had started to deteriorate quite rapidly?*

Yes in my left ear.

*And you were 16?*

Yes.

*Did they offer any assistance?*

Yes, Andrew Morrison. I had a sac decompression operation.

*Could you explain what that is?*

Yes, basically it is just draining the fluid from the sack in the inner ear, isn't it, and which I - we didn't have a clue what that meant or anything back then, but he the way he described Meniere's to me was it is not life threatening. You can live until you're a hundred with it, but it is a distressing illness to live with. And the operation I had was, it was a temporary help. It wasn't something that was going to cure it because there is not a cure. But and it did help me for about 18 months.

*When you said it couldn't be cured, what did -- were your parents with you at the time?*

Yes.

*What did they think, did they think Oh God?*

Sorry?

*What did your parents think when the specialist said it is not a cure. We can't cure it?*

At that point they were so relieved that it wasn't this brain tumour, I think, and to know it was a non life-threatening illness. I think that was all they could think at the time was thank God, she's going to be all right. And I think because we didn't know how this illness was going to progress, it was just a relief I think at that stage.

*And at that stage, were you told that your hearing could deteriorate or were you just concentrating on the then how you were then?*

Yes I think at that point it was. I remember what bothered me more at that point was the balance problems, really. Because I was compensating with my right ear, and I wasn't really worrying so much about the hearing.

[17:01]

*Were you offered any balance therapy then?*

No, no.

*Okay. So, you went home?*

Yes.

*Tried to live a normal life?*

Yes.

*How did your brothers react after their sister had been in a London hospital for a week?  
Were they concerned?*

Not –

*Did they carry on as brothers?*

Typical brothers I think to be honest, I can remember. Getting on with their lives and you know.

*But were they told you possibly had a brain tumour?*

Yes. My whole family was and I think, well everybody was so nice to me. I remember all of a sudden I was given all these presents and everybody was, you know, making a fuss and even at that stage I still didn't really realise I how serious it could have been. Sounds really strange, it really does, but I was 16. I knew what a brain tumour was, but I think it really was, really a denial thing and I couldn't believe I had something as serious as that, you know.

*Did you have a party when you told it wasn't a brain tumour?*

I remember my mum, they are all clubbed together and bought me a huge panda, which I've still got now.

*I was going to ask you that.*

I still have him, yes.

[18:18]

*With the balance problems you started 12 years old roughly. Can you remember any really bad incidence with the balance, were you out shopping at all, did you fall at all?*

Probably have been, but I just -- it is strange, but I think I have never had a sort of incident where I -- I remember one time when I was walking to work and I was crossing the road and it was early in the morning and I had one of my worst, I had a drop attack, you know, one of the worse attacks ever where I complete, my whole sense of balance was gone and everything was spinning at such a speed I couldn't focus on anything. And just falling flat on my back, in the road, and people stopping and a woman running over to me and I think that was one of the worse ever attacks. That's one of the worse things I remember outside.

*Were you able to explain to the woman what was wrong with you?*

She was actually a nurse. So I think she did have an idea, and then it so happened that my friend's brother came along in his works van, he knew me, knew I had this problem and he took me home.

*In the right place at the right time.*

Yes, amazing.

*Okay. Did you have a supportive GP? Was your GP –*

Yes, I think I was always fairly lucky really. No, actually having said that, when I was young and I first started having these attacks, no, I don't remember his name but in Cardiff he wasn't because he is the one who kept saying, no, no, she is all right; she is will get over it and that's when my hum had to get quite argumentative with to insist I was referred, but since then, I can, yes, I have had -- everybody I have seen has always been pretty good.

*And what about hearing aids, obviously you are told from the hospital you have Meniere's disease, did they start to do hearing tests then?*

No, it is really strange, I didn't actually have -- they seem to be concentrating more on the balance problems, and not a lot was actually said about my hearing in the beginning that I remember. And I wasn't offered any hearing aids at all when I was young.



*Okay. So we will go on to the stage where you left school. Obviously like most teenagers, nightlife, discos, clubs?*

It is strange because we moved to Cornwall when I was 16, and that coincided with me leaving school to move to Cornwall, and then I had to sort of adjust to coming from a city to this little place called Bude. And I actually started to work for Boots the Chemist, got a job in Boots, and because I was that was I was feeling so much better for the first 18 months after that operation, I made friends and I actually did go to discos which is amazing really. Because with the, it is probably a lot of people might have avoided it but I didn't. I wanted to get on with my life at that age. So I carried on doing as much as I could, like my friends were.

*You didn't let it take over your life at that stage?*

No, not at all not at that stage.

*Can you discuss with me why did you your parents move from.*

For guesthouse.

*For a guest house, okay, and did they do, had they had an idea how to run a guesthouse before then?*

No, never had any experience at all before. My dad always wanted to live in Cornwall. It was one of those things always wanted to live in Cornwall, and my mum had two had two sisters and the idea was that my mum and her two sisters would run this guest house and that's what we did. So it was a case of selling 3 houses to buy it, you know, but and it worked for a while. But in the end they sold up and but we stayed in Cornwall.

[22:22]

*Okay. You then got into your teens. What about your husband, how did you meet your husband?*

I didn't meet Chris, well, me and Chris were friends before we actually got together. So I when I moved to Cornwall at 16, I had met other boyfriends and then I had one for four years. He was very supportive actually I must admit; he was very good with my problems. And friends I made were, you know, because I had some attacks when I was actually working in Boots. And everybody was pretty good, but the hearing then again I managed because I have my right ear all the time, you know, so I was always my left really wasn't much good to me at all then. But I had my right and I compensated, but the tinnitus started when I was about 18. I had no tinnitus up until then and tinnitus started and that made things more difficult for me.

*What sort of tinnitus do you have? Can you explain?*

I have got pretty bad tinnitus now, from that age on, the tinnitus was bad and I remember when I was about 19, I had a horrendous stage of it, where it was so bad that affected my hearing hugely in my right ear as well and I do remember not being able to understand what people were saying to me then and that was the noise was like a, I suppose it was like an aeroplane flying around in my head. It was really, really bad and then I struggled with work big time then. Because I was constantly saying pardon to people, but I still wasn't offered a hearing aid at that stage.

*I no, it was quite poor that. So how did you go about getting, were you still in constant contact with the hospital at that stage? Because obviously you had moved from Cardiff or your initially...*

No, I think I was referred then to Plymouth, if I remember then, yes I think I was referred to Plymouth. I must have been yes. Because I had very, very good consultant in -- it was Green Bank Hospital. I don't know whether it is there any more actually, you but he was lovely, really such a wonderful supportive consultant in every way.

*Did he know what Meniere's disease was, because a lot of consultants do not but he had an understanding of it?*

Yes, absolutely, yes.

*Did he put you at ease?*

Yes, yes totally.

*And at that stage, did hearing aids come into?*

I started to see him regularly then, I remember. Because it led me, to me having a second decompression in 1985, in Plymouth. And he performed it, but he actually made no difference whatsoever to me. It was no help at all that one.

*Were you aware because I will notice you have been in contact with the Meniere's Society obviously at a later date you started doing that, but were you aware those operations don't always work or did you go on it really hopeful?*

With the first one in London with Andrew Morrison I think I thought he would sort me out, because I was 16 and I only just found out I had this illness which I not, didn't know anything about and I thought the operation might have solved the worst of it. But by the time I had the second one in 1985 I knew that, you know, it was hit and miss, some people it helped; some it doesn't and you know.

*So you had a good understanding that –*

Yes I did, .

*That's good. And how did you find the medical staff? Was it a long stay in hospital?*

Fine, they were all really nice, yes.

*Did they take into account your deafness when you were in hospital? Did they face you or realise you had a hearing problem?*

You mean the nurses?

*The nurses, yes.*

No; no because I think still at that stage my, because my right ear was fine, I was coping fine. I had learned totally to compensate with my right ear, so, but Mr. Bridger then sorted out hearing aids for me. He was the one who referred me to the audiologist and it went from there then.

*How did you find the audiologist on your first visit?*

Lovely, really nice.

*And did they, you obviously had the two hearing aids?*

Yes I was given two, yes.

[26:57]

*How did you cope? Hearing sounds again?*

Not, it is not very easy because I had the first ones I had was the analogue back then, analogue hearing aids, and it I was supposed to wear them both, but I tended to sort of not bother with the left. I was being lazy because I got used to not having hearing in my left ear. I managed without it, so I can go on managing without it, but I learnt later on that is not what you are supposed to do. That you are supposed to have the two, because I have still got a small amount of hearing with higher tones and you should have the two for the balance shouldn't it, so I did learn that later on.

*Were you married at this time? Can you remember?*

Yes, I would have been yes... no, no I wasn't, no.

*That's OK.*

We were engaged then.

*You were engaged?*

Yes.

*So, how did your partner –*

He was really good.

*He was good.*

Always very considering, you we started seeing each other about age 21 I think and again he knew me with it from day one. So it was sort of part of me I suppose and he was always really good.

*When you met him and started going out you explained to him your problems?*

Yes, yes.

*Did he have an understanding of it at all?*

No, he didn't have a clue.

*Has he always been healthy?*

Chris, yes, yes until recently when he has had a few problems, but only sort of.

*But his hearing is fine?*

Yes, absolutely fine yes.

*Your children's hearing?*

Touch wood.

*That's all fine?*

Absolutely. Touch wood, yes, because I remember asking Mr. Bridger that, you know, is it something that you can pass on? Is it hereditary because it was my fear, but he they can't say, answer it, can they, really.

*No. I was going to say I will come on to that when we have finished because I have learned something recently, but I will tell you that later.*

All right.

*So, yes, so you got offered these hearing aids and still working in Boots?*

Yes.

[29:03]

*How did you cope with customers with the noise coming from the hearing aids?*

Well I got –

*Or one hearing aid should I say?*

Yes, exactly. But when the tinnitus calmed down, and my hearing was fluctuating, you see, so I wasn't wearing them all the time, but I did get I don't know, there is a name for when your hearing gets sensitive. I can't remember the name of it.

*I understand.*

I did have bouts of that, and that was a nightmare in the shop, because it was simple things like money in the till, which sounds silly; but when the money went in that noise would make me, it was like somebody clanging something about in my head and that was awful. And like when you're picking up bottles on the shelf and the bottles clang together and it is and again I

used to put up with it and not say anything. Because I thought I can't keep on saying this is bothering me, that's bothering me.

*Did you get headaches with your hearing?*

No.

*Did you have much time off from Boots?*

I managed pretty well because I worked full-time for about 8 years, and I did manage pretty well. But towards the end of that in the last year I had 18 weeks, I remember, which I thought was loads and I got very conscious of it.

*How did your employers react with that, were they understanding?*

I ended up being sent to the, what do you call them -- their own doctors, Boots' own doctors. I can't remember, and to be assessed. And then what I decided to do myself was go part-time. Because I couldn't cope with the full-time any more.

*Did you still live at home at this stage?*

Yes.

*And you, did you experience any problems indoors at home?*

What do you mean?

*With the hearing aids, with sounds and –*

I never liked them. I never ever liked them and I used to go without them as much as I could, because back then, like I said, my right ear was still okay. It was my left that was all my problem.

*Yes, so I notice you say about the tinnitus; you were giving a masker. Was that years later?*

No. I have had my masker for years; I have the old original one which I still use now. But I have had that for at least 27, 28 years.

*How did that come about, getting the masker?*

That was would have been Mr. Bridger as well I should think. Yes, right at the beginning, he gave me the masker and that has been very helpful at times and sometimes I have really needed it.

*Have you tried aroma therapy or other –*

Yes, I have tried, I have tried acupuncture. I have tried reflexology, I have tried homeopathy over the years and none of them have really made any difference to me.

*We have mentioned the problems you had at work with the hearing. You eventually got married?*

Yes.

[32:08]

*Had children?*

Yes. I was really well in my pregnancies, that was the strange thing, yes.

*It didn't affect the Meniere's at all?*

No, I seemed to be well, weller when I was pregnant because I remember Mr. Bridgers saying, you should have about nine children! I remember thinking that's a bit drastic, except my eldest Nathan, who is 22 now, the tinnitus got really bad towards the end of that pregnancy and when I was actually having him it was horrendous, extremely bad, and my hearing was extremely bad. But it was probably the pressure because I can remember the



nurses looking at me, thinking I was mad, because instead of complaining about having a baby, I was complaining about my ears!

*Did the nurses take any notice of that?*

Yes, well, the one was talking to me like I was completely stone deaf, I remember it. And Chris got really ratty.

*Good.*

Saying she is not stupid, she is deaf and not stupid, I remember Chris saying that.

*Yes, the nurse come back with a big injection. Okay. So about your right ear, you're constantly having problems with your left ear?*

Always my left, yes.

*So when did you, what age were you or how did you notice the right ear started to –*

I think I was, I convinced myself that my right would always be okay. And then I remember, I think it must have been early '90s. All of a sudden, my hearing dropped in my right ear and I do remember the time it happened because I think my second son was about 2 at the time. So that would be about 16 years ago. And I remember on the phone, for instance, thinking I am not hearing as well. And it was horrible. I remember thinking, oh my God, but and I saw Mr. Bridger and then he gave me more hearing tests and then he said to me, I am sorry but it is showing signs of going into your right ear, which I remember now and I was totally devastated. And I remember coming out of that appointment just absolutely, I couldn't believe it.

*Was your husband with you?*

No, I was on my own then, yes.

*So...*

I came home and went to tell my mum. I remember sitting with mum and saying I don't believe it. But it is really strange because I think I went into another self denial mode and I didn't want to believe that my right ear was being affected and I kept thinking, no, he is probably wrong, which is weird for me, really, but I just didn't want to believe my right ear was going to become like my left. But then the hearing improved, classic of Meniere's, and I had several years then of it all right again. So that's when I was convinced he was wrong.

*Have you read any books on Meniere's disease?*

Yes, yes.

*Have you gone on to the Internet to look?*

Yes. Done all of that, yes. I think I just about know all there is to know about it now I think.

[35:08]

*Okay. So going back to the after you had your children and you started losing your hearing, what about hobbies and leisure at that time? In concentration?*

I read a lot. But then I mean, that's nothing to do with hearing. I am –

*It is really because of concentration with tinnitus. Did you find the tinnitus made you lose concentration?*

Yes, sometimes, especially at night when you get tired. Then that's the, when at night when I get tired and it increases then everything is difficult.

*Do you have at night, like, what do they say? They advise to listen to soft music, which I find ridiculous because we are deaf!*

Exactly!

*Have you tried those sorts of things to –*

No. I just use my masker. I put my masker in and I concentrate on that noise, knowing it is an external noise. So to sort of convince myself it is going, the noise in my head. It sounds silly but I think eventually –

*Yes, and going back to hobbies, did you have any apart from reading did you, because you were quite sporty, well, you liked to run in the horses?*

I was into card making and I walk my little dog all the time. And I love walking. I walk a lot.

*You've got some lovely places to walk in Cornwall.*

I like writing. I have taken a couple of writing courses, so my big ambition is to write a novel. But it will probably never happen.

*Lovely, yes. You could write about Meniere's disease.*

I could do that, yes.

*There's not many books about. Your parents, all through this, they have been very supportive you say?*

Fantastic. My mother is a Godsend. She I wouldn't don't know, I do not know what I would have done without my mother over the years, absolutely. Because she had the fantastic combination. She didn't molly coddle me, wrapped me in cotton wool when I was younger. She encouraged me to go out and do whatever I could because I remember lots of people say, Oh, you know, why do you let her do this, where, she shouldn't go to work or could do this and mum would say, if I kept her home she wouldn't have a life! But she has always, always been there for me. One hundred per cent.

*Has religion played any part in your life at all?*

Only when I am having a bad attack, praying to be okay, I suppose, but I do believe and all that but, you know, I haven't got a strong faith in that sense really.

*And what about politics, are you do you –*

No, no. Not into that, no.

[38:04]

*That's fine, I had to ask. So, you struggled on at work in –*

There have been lots of -- struggling became part of my life, basically. And but when I was younger, like I have told people all the time, I used to bounce back so much better from all my attacks and my bad times, because when you are young I think you cope. I just think you do. What I have learned as I have got older is I have not coped as well, especially since losing my right ear.

*Can you give me an example why you think you haven't coped?*

Yes. I mean, since I think I would probably say since my right ear got affected, so then I knew I had it in both and that was that, when I knew that was happening. And then the attacks were horrendous, again; from this side from my right side. I mean, I just lost total confidence in everything and I was, I did get on with suicidal. I know it sounds dramatic, but I did. I got to the stage a few times probably going back a few years when I thought, I can't do this any more and I really, really had enough. Which was a horrible time. That was absolutely horrible. And it is horrible for everybody around you as well then.

*When you had those feelings did you talk to your mum?*

Yes, yes.

*Did she understand?*

Yes she did yes.

*What about Chris?*

I don't think I actually told Chris that I felt like that. Because he has always been very fortunate that my mother's been there and mum has taken a lot of pressure off Chris, because to this day he has never lost a day off work to be home with me, because mum's always been there for me when he hasn't been and he sort of had to do the night duties when I have been really bad. And he really has lost a lot of sleep and he has been brilliant. He has sat by me for hours at a time, when I am having one of my spins and trying to reassure me all the time. But I have found it harder as I have got older. There is no doubt about it, and I do not bounce back like I did. The last bad phase I had went on for about 18 months and I did think I was going to go mad, because I thought it was never going to stop and it was a horrible time, horrible.

*When you were going through that bad phase, were you trying to obviously you were trying to be positive. Did you think of the future or your children when you were going through the bad phase, or were you just thinking this is never going to end?*

Yes, that's what I felt like; I thought this is it now. This is probably how I am going to be, because my hearing had got so horrendously bad then, that I was wearing the two hearing aids and I couldn't understand basically what anybody was saying to me. So it was like being in this world of and the distortion was at its worst. So I couldn't hear the telly, I couldn't hear music which I love, I was missing music. I couldn't understand what Alex and Nathan were saying to me. They were getting frustrated with me because I would say, 3 or 4 times, "pardon", and then they were like "oh never mind, never mind". They were teenagers and couldn't be bothered and it was all, just I felt useless, really I suppose. And hopeless. I was really did feel it was like everything was pointless.

*But you are not alone in that, I sympathise with that.*

No, no.

*I sympathise with you on that, I understand fully.*

*You have a very supportive family.*

Yes, very.

[41:48]

*So, during that 18 months how did you find the medical profession?*

Well, there wasn't anything they could do. There was one, only one there was one incident with my GP, who is a good doctor. I have always found him a good doctor, but in this stage when I was so bad and I didn't know what to do, I remember going to see him and first time ever I burst into tears, sat in front of him. And I told him, I am at the end of my tether; I don't know what to do. He was hopeless, absolutely totally hopeless. He didn't know what to say to me, or do with me and he was just sat staring at his computer and said, I will refer you. And I thought, refer me for what? You know, and I suppose I don't know what I expected him to do or say, I admit, and I came out of there feeling a hundred times worse before I went in.

*Have you thought of counselling?*

I have thought about it but no one ever offered it to me and I never asked.

*What about medication? Do you take the Serk?*

Yes. I have tried all the medication and they never did anything to for me. I tried Serc, and I take stemetil, when I am not well, Buccastem I've taken but I prefer to take stemetil, but that's about it really and I have been on anti-depressants when I have been really bad.

*Yes. Okay. When you have your bad attacks, like the drop attacks, are you violently sick with them?*

Yes.

*Do you get administered injections?*

I have only ever had one. When the doctor came once and give me a stemetil injection.

*They have never offered that to Chris to do it to you?*

No, funny because my sister-in-law is a nurse and she has often said that to me, can you do it yourself or I can come and do it for you. But no, I did ask my GP once, but he never actually followed it up.

[43:42]

*Okay. So moving on to the present time then, at this moment in time you are –*

In a better phase apart from the tinnitus, that's still horrible.

*How is the hearing in the right ear at the moment?*

In my right ear it is better than it was, because I think a lot to do with the, because of the distortion is down. It is still. I mean, you are close to me now. I can hear you, if you were a bit of a distance I wouldn't. If I am in a group I struggle, but I do when it is like this, I don't put my hearing aid in. I admit, I don't. Which I probably should really, but I don't.

*I won't tell you.*

I have my left one in now, but not one in my right.

*So going back, so we are in a group with a Christmas lunch or something and you are having a –*

Exactly.

*You are having a bad time, how would you cope?*

I find it a nightmare. When I was in my bad phase and I did go out the few times I did, it was awful. Just awful and I would say and I couldn't understand a word anybody was saying and,

at the end of it, I was exhausted. It actually makes you feel physically and mentally exhausted, you know, because you are struggling so much to hear, and it is just not worth it really.

*No. And did the people you are with, did they try to involve you in the conversation?*

Yes. But the trouble is the people do that in the beginning, and then they forget and then they carry on talking and it doesn't remain, you know, I mean anybody I mean, since I have been in a better phase I have done I have been out loads with my friends, I go as much as I can. When I am in the better phase and they all know that, because I tell them when I am in a better phase I will do that. I will do that and I do, I like to say yes to everything. But if a bad phase kicks in again, then they are going to see the other me then and I can't, but I don't, I am not embarrassed any more; or ashamed of it or I don't care what anybody thinks. I learned that over the years. When you, I was younger in my teens and perhaps early 20s, I was a bit embarrassed about it and didn't want to tell people. But since I got over that, I don't, it doesn't bother me at all.

*And with communication, have you had any problems with communication? If you go into shops etc, Or –*

When it is bad, yes, yes.

*Can you just tell me a bit about that?*

Well, it is just it is, I mean, in a lot of shops you can have background music can't you, or and then I it is just understanding that is, when the tinnitus, sorry, the distortion is bad, it is you -- I cannot understand what people are saying and it is just, it is just uncomfortable and I will try and avoid it. I just try and avoid those situations.

*What do you say to them? Excuse me, I can't hear you?*

I will do yes.

*Did you do that when you were younger?*



No, probably not as much.

*You weren't confident enough to do it?*

No.

[46:45]

*Okay. What about your, when you were at school, have you kept any school friends up to the present day?*

Yes, yes.

*They are still aware you have got problems?*

Yes absolutely.

*They are fully understanding?*

Yes, I think as, yes, because and the friends I have now in Cornwall, they have never known me without it obviously. So, it is like I said, when you start something so young, they know and they are all really good. They do understand, the best they can but I think unless you experience vertigo attacks it is very hard to explain how bad they are.

*Okay. And who, you have heard of LINK?*

Yes, yes.

*Can you tell me how that came about?*

How did I find about LINK? I think I just seen one of the leaflets, I think. And I contacted Lisa, I think Lisa Jones if I remember, very nice, very supportive, very helpful. She got back

to me straight away, but it was E-mail because I couldn't use the phone when, you know, and she did offer me the, that course.

*Intensive programme?*

Yes, that is right, the intensive programme. But at the time it was offered to me they didn't class me as deaf enough, to actually be and it was I think it came down to my GP and I think because my hearing in my right ear was, you know, fluctuating and I actually didn't get put into for it at that time, but she has always told me that any time in the future, if I got to that stage, you know, it's still the option, the option is still there.

*Okay. Would you be happy to go on one of the courses?*

Yes definitely.

*You would. Okay. Because would Chris be happy to go with you?*

I think so, yes.

*Has Chris ever tried to understand what you are going through? Hearing wise?*

Yes, because I mean the stages when I have had to have the subtitles on the telly, and in the end everybody had to watch telly with subtitles because of me. And I think in the end they all got quite used to it. At the moment, we don't and I do. Trouble is I need a telly a bit louder than he does, but I think he's got used to that with me as well. So...

*Okay. Have you been contacted by Social Services at all about loop systems?*

Yes, yes.

*How did you find them? Were they supportive?*

Yes very good. I have got the, in the ear things for the telly and they give me the bell for the door that flashes because when things were bad, I couldn't hear people knocking or anything.

So, that was really good and I did use that for the telly but it was hopeless with the distortion, so it had to be subtitles, you know.

*Okay. And how do you manage with the telephone now?*

At the moment I can use it on my right ear, pushed right against my ear and if it is a fairly good line and then I can manage.

*And are you one of these people who can do all this e.mail stuff?*

Yes, I went on a course for that because I have to learn to do e.mail because in my bad phase, it was e.mail and texting only. That's all I did. I couldn't use the phone for anything. I just have had to ignore the phone totally.

[50:06]

*I notice you are attending lip reading classes?*

Yes, yes.

*How did that come about? Were you recommended to do lip reading?*

No, no I just found out about it myself. It was something I should be doing I thought. At the time I went funding was covered and they changed it and I wasn't covered any more, and it was also at the same time when my balance was bad again, and that has stopped me going. So the combination of the two stopped me going. But I do not know whether it is actually still going now. I don't know whether or not enough people were attending, but it is something I would like to do again because I know it is I think it is important.

*Yes. We said earlier you found it difficult?*

Yes.

*Because you found it difficult, did you feel I can't do this?*

No, no it wasn't that, no, it was because they were a nice group of people. And the teacher was lovely, she was a lovely teacher, but it was just again because I was not feeling well such a lot I was avoiding going to a lot of things at that stage. And it got to the point and also I was not driving and it was a bit of a distance to get to. Chris was working and I had problems getting there and it was a combination of things stopped me really.

*Would you class yourself as disabled?*

In my bad phases yes, definitely. Definitely then. That's what is so complicated with Meniere's though isn't it? Because you have a good phase and bad phase and when you are in a bad phase you are disabled; life is so difficult. When you are in your better phases you cope. And I think this is what people find hard to understand because they say to me, well, you look all right. And I said, yes, but you can't see what goes on inside my ears.

*No, we call it a hidden disability.*

Yes it is, yes definitely.

*What about negativity, are you a positive person?*

I am naturally a happy person, I am, I am not miserable. I like to be positive about things, and I, you know, but when I am in a really bad phase, then I am pretty negative. Although I was last time anyway.

*And travelling, how do you find, I mean, obviously when we have when you have a spin attack you can't drive?*

No, no.

*Can't do anything.*

I hardly drive at all now actually.

*You rely on public transport?*

I don't like to go on my own when I am in a bad phase. When I was younger I did. Again, that's the difference getting older and losing confidence and, you know, I still when I am in a bad phase, I don't like to do things on my own in case. So it is always in case.

[52:57]

*Yes, so if you had an appointment in Bude, and you felt I didn't really want to go on my own, would your mother go with you?*

Yes, my mum or a friend, I always find somebody, always.

*Okay. Would they when you got to that appointment would they help you? Or would they make you do it yourself?*

I would go to the appointment on my own. It is just having somebody sort of there to go and come back really.

*And what about hearing, I mean, if you were in an appointment and you were struggling with your hearing, how would you communicate?*

Just by asking them to repeat what they are saying and concentrating more, that's how I have done it before really.

*Would you consider using note pad and pen?*

Probably, yes, I would if I needed to, yes, when the distortion is extremely bad.

*So, the next question I was going to say to you, has it changed your life but in a way you have grown up with it, so you have adjusted.*

Exactly, different so to so many other people because of starting at such a young age. It's always been part of my life. And that's why I think I when I have had these, the last bad

phase I had I think I got to that point where I thought, you know, 35 years of this is just ridiculous and I was feeling really hard done by, I suppose, and I have had lots of times when I have been very bitter about it, I have to admit that and angry and I have thought why did I have to get it so young, it's not fair. I have had hundreds of times like that. And but then again I say to myself, well, I was lucky to have such a supportive family. I have always been so grateful for that. If I haven't have had that, it would have been so much harder.

When I am in my better phases I do enjoy my life, I do, just wish they would go on for years.

*I know.*

Because some people are lucky enough to have years of remission, but I never have. Never had more than 18 months and that's why I get start to get jittery after I have been well for a while because I am kind of waiting, which is awful, I think.

[55:12]

*Do you have any regrets over your life because of the Meniere's?*

Yes, I think it stopped me doing more when I look back. I mean I always loved dancing, and I think that maybe if I hadn't have got Meniere's I would have gone on to do something with that. But because it started at a young age, I didn't feel I could do it. So yes, I have got regrets because of it and I suppose there are times when I will blame it, but whether or not it I would have done these things anyway I don't know. I don't know.

People say to me, how did you have children with something like that? And I say, I didn't give that a second thought because I wanted them, and, you know, and like I said my mum again was supportive when they were little and I wasn't ill mum was brilliant, so...

*Has it affected your personal life with your husband?*

No, he has always been really good. We have been married nearly 23 years now and he is, there is only perhaps in the last bad phase I had we were doing a lot of things in the house. He was doing it all and I think there was a stage where he did get a bit tired of me, because I went on a long time unwell. And but that's the only time ever I think he has lost his patience a bit if you like.

*Which is natural.*

Yes, yes.

*Okay. Discrimination, that is a touchy subject, obviously you said Boots have been very understanding.*

Yes, yes.

*They were and did you feel discriminated at all?*

Not really, no. No not really. I don't think I have ever really felt like that being honest.

*That's good. What about public, how have you felt with the public when they have come into the shops?*

Fairly good really. I have never had a bad incident. I have never had any thing that I can really say upset me terrible or you know, to do with my problems, not up to now.

[57:14]

*Have you flown?*

Yes, I don't like it. Because purely because of my ears, I worry myself to death about it. I went to Spain last August with a bunch of girlfriends and actually I remember when we booked it a few months before I was petrified booking it, because I didn't know whether I would be well enough at the time. It is that constant fear and I said to them all, look, I don't know whether I will be going on this holiday with you because if I am not well I won't get on that plane. Anyway, I was lucky. I stayed in a good phase, but I am sucking sweets, I've got the ear plugs in, I am I got Vick under my nose, everything. And I hate it, I absolutely hate it. I must admit.

*What about when you were in Spain? Were you constant that you could suddenly have a drop attack or spin attack or did you put it in the back of your mind?*

Last year, when I went with my girl friends, I had a good week. I didn't worry about it because I did previous to going but I think once I was there, I was determined to have a good week and I did. It was a lovely week.

*Yes. And what about the hearing when you were in Spain? Was that quite good?*

It had come up, so I managed. I mean, we didn't go to many noisy places. We went to one club on the last night and they had tribute bands and that was loud because I have trouble with loud, if something is really loud because it puts my tinnitus way up. So the next morning when I got up when we were flying home my tinnitus was very, very bad and I was struggling to hear what everybody was saying then, mainly for tinnitus. So...

*And when you were on the plane, did you experience earache at all?*

No, no. It is funny I don't actually, no.

*Not taking off or landing?*

No, because that's what I am worried about all the time and obviously worry is going to make me feel dizzy. But the only feeling I don't like is when the plane moves. But I think that's just, yes, it is just one of those things, a lot people I know don't like. But I am more aware of it I think. And I am just sort of prepanicking I think! My friend was holding my hand, you will be all right, you will be all right.

[59:35]

*Okay. You have mentioned earlier about the Meniere's Society?*

They are wonderful. Can't praise them enough.

*Have they discussed hearing loss with you as well as the Meniere's?*



You mean personally?

*Personally.*

No, I have I joined them in 1986, right at the very beginning. I think they haven't been going for very long, and I was through the television programme in that I wrote to somebody I remember they gave me the address, but mainly been through the magazines that has been the support with me.

*The Spin magazine.*

Yes the Spin magazine.

*Have you had any articles published in the spin magazine?*

Yes, several, yes.

*You find that a comfort?*

Yes.

*Receiving a magazine.*

Yes definitely, absolutely.

*Makes you feel you are not alone?*

I think they are brilliant, yes.

*Have you, the advice they have given you, you say you have spoken to them over the phone or e.mail?*

E.mails I have yes.

*The advice has always been positive?*

Yes, very. Yes.

[01:00:40]

*Emotions and frustrations, I should imagine you have had lots.*

Frustration is the biggest word I think, absolutely, frustration.

*Can you elaborate on it a bit?*

So many times over the years I think frustration is probably the biggest emotion really, isn't it, because it is the, because Meniere's is so unpredictable. You cannot predict what is going to happen from one day, one week, one month to the next and I think when you have begin a good phase, the minute a bad phase kicks in again, I feel massive frustration because I know then what's going to happen and how I am going to feel and how it is going to change things for me and I think the frustration then is that I can't do the things I was doing. It is -- and I find it, if I talk to a couple of friends that have got it and they say exactly the same thing.

*If you have been in my experience. We are talking about yours, I know. If you arranged to go for a meal with Chris and unfortunately you are all prepared to go, Meniere's comes up and you think, I can't go, how do you feel?*

Mad. Angry, frustrated. That's frustrated is the word then. And disappointed, it is like a huge disappointment if you are looking forward to something. I mean, it was like New Year a couple of years ago, we were going out, I had my bath. I was just going to get ready and my head went and I couldn't go. I thought fine, I will stay in with the kids and then and Chris.

*You would let Chris go?*

Yes, funny enough, it is probably for the best because it would have been noisy and full of people and all of that, and but it I suppose I haven't had hundreds of times like that. I think I have been quite lucky. But when I am in a bad phase I tend to avoid things. I am very picky what I do then and who I am with.

*I know you can't arrange things in advance, but. ..*

No. That's one of the worse things with Meniere's, is the not being able to plan. I panic if I plan I panic and I do, I always have. I get really scared to plan anything, because I am one of these people I am afraid that thinks it is going to tempt fate and then something is going to happen to spoil it. Terrible for that.

*Yes. And going through a bad phase with your hearing, you say when you're going through that, you can't, the hearing aids are uncomfortable?*

They are terrible because they pick up, you pick, they pick up absolutely everything and when I think with Meniere's the distortion has to be one of the worse parts with that comes with the bad hearing. And I can't, it is not just not hearing. It is not understanding, all I get is like everything is so unclear and it is, I get, it is exhausting. I actually do feel really exhausted by the end of the day. With the constant struggle.

*What is your relationship with your hearing therapist?*

Good, yes they are really lovely. I go to Bodmin and they are so nice there. I have Jane my hearing therapist she is wonderful, lovely, lovely lady. She got me digital hearing aids very quickly, very quickly and I have always been grateful for that. She is a lovely lady.

*Did they understand Meniere's?*

Totally, yes, yes absolutely.

*Okay. What about other social groups? You said I think you said you did creative writing?*

Yes, I did. Yes I started a creative writing course a couple of years ago and when I started my hearing wasn't so bad. Half way through, suddenly drop and I struggled big time. And I remember sitting in the class about 12 of us, and I really couldn't hear and even when I put my hearing aid in, I just couldn't and because people were reading out things they had written. And I sat there thinking this is dreadful and it spoilt it for me, so that again was a frustrating time for me. Because I didn't go to the last two I think, because I just couldn't hear, so.

*Yes. Did you before you started a class, did you explain to the tutor?*

No I didn't.

*Why?*

I think I did half way through. I did I think tell her I was struggling.

*Because of confidence or embarrassment or?*

I think it was difficult because we were sat in like a table like this and she was in the middle. So I think I sat in front of her thinking that would be the best, but it wasn't and I think she would forget half way through and turn to the board and write things and I thought I can't, I just can't and I just got so fed up. I was so angry because I was really, really enjoying it.

*Yes. Could you not do it again? And explain why?*

I would do it again, yes. I have been doing a home one, but I actually quite like going out to a class. I quite like that part of it actually.

*It is the interaction.*

I am not really good at studying at home. I tend to get distracted.

[01:05:52]

*And how do you find the cinema?*

Awful, absolutely awful. I went the last -- I hadn't been for a long, long time, and then it was last year, we went to Plymouth to the big, big one and of all things it was the new James Bond movie. It was horrendous. I couldn't wait to get out of there. The screen was so big. I spent the whole time like that. I couldn't bear it because with all the and the noise. My God, I should have walked out, but I stuck it but I was like that the whole time. So I shan't go again to the cinema.

*Stage plays?*

I like them, but I again I won't go when I am in a bad phase because the hearing thing is too much of a problem. I wouldn't understand and if it is loud I can't bear it. Can't bear it.

*What about fluorescent lighting?*

I do not like it. I don't like supermarkets, don't like any of that. I mean at the moment in a better phase I go shopping on my own again now. In a bad phase I have to have somebody with me, because usually I have to get out of there as quick as I can.

*Have you discussed all of that with your hearing therapist?*

Yes, I go round actually with sun glasses on which looks ridiculous but it is just to cut the glare out.

*No, no. So through 32, 33 years of roughly problems that you have had?*

Yes.

[01:07:22]

*Over all the medical profession.*

Been pretty good, yes. I haven't got many complaints, I must admit. Michael Bridger was a wonderful, he was lovely. I can't praise him enough. He did everything he could to help me, he was so supportive. And he told me whenever I needed to see him, he was there for me and he was lovely. My GPs have been pretty good. The one I have got now, he's not got the best bedside manner. But he is fantastic at referring you, he will do that. I only ever saw one specialist years and years ago who I didn't like him, he was very abrupt, very off-hand and I didn't feel comfortable with him. But that was a long time ago and that I can, is probably the only one. So on the whole, my hearing therapist, like I said, she is wonderful. The audiologists in Bodmin are lovely, very helpful, very patient, explain everything properly. So, no, I can't really complain.

*And you said you, with the telly you use subtitles, probably like me. What about music?*

Oh, when I am in a bad phase, no way. I can't even I can't understand the tone or the tune, what they are saying, and I that is the most, one the most frustrating times for me because I do love listening to music, absolutely and I have had times when I have really have been in tears over that, big time. But when it is a bit better, like it is now, I can put music on and I can hear it with this ear and it is the distortion when that is bad, you haven't got a hope. Do you find that, not a hope?

*I do, yes, definitely, yes. I don't even play my music now.*

You don't now, no.

*Because it ruins it.*

It does, exactly, it is pointless isn't it?

*It is, yes, and like you I get tearful and why me.*

It does, it gets you very angry, because music is something that helps you in lots of ways, when you are down if you play music, but with us you can't, it is –

[01:09:33]

*So with three lads are they still at home?*

Yes, well Nathan works away during the week, but yes they are still at home.

*They like their music?*

Yes, yes, Alex especially.

*Do they understand now they are older, do they feel they have helped you enough?*

I don't think they think about it, I have to be honest. I don't think they think about it.

*Do you tell them how you feel?*

Not a lot. Being honest, no, I don't like to bother them really. I think no I don't really, they have seen me really upset lots of times. They have, you know, and my youngest, Luke, is still very cuddly. The other two are sort of gone past that stage I think. So they don't quite know what to do, sometimes I think. But I have never really, no, I do not really go on to them about it really.

*Just to touch on what you said earlier about you were quite low when you had a bad attack. You said you, Chris was very supportive but he got a little bit –*

Yes, this one stage yes, it was because he was very -- we had a new kitchen put in. He was doing all the work himself. And I had been bad for ages. And it was really bad. He had been up nights with me, hours at a time. He was tired. And then I think he did get and then my mum came round one day. I can remember and I was upstairs crying and crying, sat on the floor because I had an attack, and she said "look, come home with me for while". That was the first time ever I did. And I went back to mum's for a few days. Just to give Chris a bit of a break.

*How did the children react to that? They must have seen a difference in mum because usually the strong mum who was able to cope with it before?*

Yes, it does. It affects them and they, I mean, like I said, mum is only next door anyway. So obviously Luke would come into me then.

*They must have realised mum had gone to stay for a few days?*

For a bit of a break, yes. But I just said to them I just need me and dad need a bit of space. He can get on with what he is doing and he doesn't have to sit up with me, whereas mum would sit with me then, you know, but she is 78 now, my dear mum. She's still fantastic. Like I keep saying, but you know.

*Do you feel you let the children down at all?*

No. No, not really no I wouldn't say that.

*And through their schooling you?*

They have been fine, they have done really well, really really well, always enjoyed school and done well. Which I am glad about. Very confident my boys, thank God.

*Their ambitions are?*

Nathan, I mean, he did really, he got ten GCSEs, 3A levels; wanted to go into the RAF, aimed to be a pilot. But he is now a builder and he loves it, absolutely loves it. My middle one, Alex, he is in his A levels now, coming up now, but he is not enjoying studying any more. He is fed up with it. And my little Luke is my ray of sunshine. That's how I describe him. Because he is so bubbly and cheerful all the time. He is a lovely little boy.

*How old is he now?*

He is 13, he is only little like me.

[01:12:54]



*What is your view for the future? Obviously with Meniere's, it is very unpredictable.*

Totally yes.

*You could lose all your hearing. It is possible, we know that.*

I have to admit, I can't bear the thought of it even now. I know that it is very likely that this is all going to -- it will go again and I will be back to what I was like before. But I think, in all honesty, I could learn to cope with the deafness. I just wish the, it is the attacks the vertigo attacks are the most horrendous because they disable you totally, don't they. Being deaf, you are disabled to a point. But you are not disabled like when you're having a vertigo attack and also I think my confidence could build without the hearing if I knew I could go out and do things and not get one of these attacks.

*Similar to what you said earlier, you learn to adjust with it. But when you are younger you seem to be stronger, able to adjust a bit more.*

Definitely. And I think that's maybe because you don't look to the future so much, you don't worry so much about what is ahead and you just presume everything is going to be OK, perhaps in a way. And then when you get older, you haven't got that sort of sunny, so much of a sunny outlook and I think is when I realise this is with me for life, I think. And I am always going to have these bad phases which I know now and I think it is, I am more accepting of it. But I still live in dread of the next bad phase. Totally.

*Do you feel that if anything upsets you in life, like we can't just all sail through life happy, do you find emotions upset make the Meniere's worse?*

Stress, yes probably does. Stress levels can and the tinnitus I am sure does get affected. But I don't know whether I would say probably not the hearing, that wouldn't, no. That is just one of those things.

*You just think it fluctuates because of the Meniere's?*

Yes because of the Meniere's.

*How do you see the future?*

I don't know really. I probably just go along as I am and I just hope that the next bad phase I do have won't be as bad. I don't want to be stone deaf or completely deaf. I must admit, I don't. It is an absolute dread because I have, you know, but I do realise that is something that can happen. And I suppose I'll just deal with it if it does, but I mean, I didn't expect my hearing to improve after the last time because it was so bad for so long. I thought that was it. So when it came up again I was, you know, I couldn't, it was strange because I didn't expect it to. I really, really didn't, so this is what, this is classic Meniere's isn't it? You just don't know what is going to.

*No, have you set any goals for the future?*

Not really. I would love to go out to work again. I would love to go out to work but I haven't worked for about two years now, at all. Because of, since the last really bad phase. Because I am just so totally unreliable.

*Yes, yes. I know.*

You just can't be reliable for an employer, and that that is not easy for Chris, because I am conscious of the fact that you know most couples they, you both work don't you? You both work because you need to. So he has to do it all and I do I feel guilty about that.

*That's what I was just going to ask.*

I do feel guilty about that a lot.

*Do you feel you have held Chris back?*

Not really. He has always been really good. He has always said, you, it is better that you are home with the boys, you know, you do everything with them and you sort them out and I am the one going out to work. So he has never made me feel inadequate or, you know, hopeless. But it is the way I feel.

*It is your inner feelings.*

It is good going out to work because it is, well, yes, I do keep really busy though; I honestly never get bored at home. I have plenty of friends I see all the time. I don't get fed up. I and I have adjusted really well to it actually, so it will probably be really weird again if I did actually now.

*You are happy in Cornwall?*

Yes, I am now, yes.

[01:17:26]

*And we are talking about work, volunteering, a lot of people with deafness we have discovered like to do volunteer work, just so to give them a community. Have you ever thought about volunteer work?*

I have actually because my cousin does voluntary work for the RNLI and I actually only recently last week did offer to maybe do something in the little shop they have got in Bude, because she does it. So maybe that's something I would do.

*Could get your confidence up couldn't it?*

Yes.

*And also, I am not selling this because but LINK actually do outreach work with, they want volunteers to do outreach work. Would you consider something with that?*

It would be the driving thing with me, where I live. I would have to be able to drive to get to and I am just not reliable with the driving.

*No.*

Because I did have a man come to see me actually, he was one of them. A man came to see me but he was not, didn't really do much for me to be honest.

*That's fine, because I am going to come on to that now actually.*

Right.

*We want honesty; none of this goes back to the office. So only to deal with the hearing what we are doing.*

*So, the LINK centre sent an outreach worker to you?*

Because I asked if there is anybody perhaps I could talk to and there was a man in, I think it was Launceston, I think that's where he lives. So he had to drive to me, and he brought his wife with him, didn't come on his own, and he was completely deaf due to an accident.

*Yes.*

He was about 60ish, something like that, and he had a beard because I can remember his e.mail address was weird because he called himself bearded passion or something and I thought, Oh, as soon as I read that I thought that sounds really odd. I don't, I thought it was a bit, I thought was what a funny, just didn't but he was all right. I mean, his wife actually did most of the talking. She was quite dominant and he was actually the, and she sort of tended to take over a bit. And –

*Did he understand what Meniere's was?*

I do not think so no, no I don't think he did.

*Did you fill in a form after he left?*

Yes.

*Were you honest on the form?*

No. I didn't like to, he said he was all right because I don't want to upset anybody.

*You won't upset anybody.*

But he actually didn't do a lot for me, I have to be honest. He didn't help me in any –

*So did that change your thinking about LINK?*

No, no.

*It hasn't?*

Because Lisa and the emails they have been lovely, really, really nice.

*Okay. I am sure they can get round the no driving part of it; if you really thought you would like to help.*

I thought would you have to get to people, wouldn't you, because I did think about it once because I have a friend in Essex, Helen. She has done it because she has Meniere's, but because –

*I do it.*

With the driving with me now, I have actually lost a lot of confidence with driving as well, and it is, it is an A to B thing. But it is rare I actually don't drive a lot now because of my Meniere's.

[01:20:44]

*Okay. If you could change anything which has just happened or what you have gone through what would you change? Or if you could do anything different to what you have done?*

Having Meniere's, still having Meniere's?

*Still having Meniere's, through experience what you have learned and obviously –*

I don't know really -- no, I think the only thing probably would be a career aspect I think. I regret the fact I never actually formed a

career, and I think Meniere's was probably the hold back for that, but not really. Not any, you know, not that...

*Anything you would like to add to what we have discussed, what we have missed out you think?*

No I think you have I have covered most things I think.

*Okay. Well, shall we end it there then and I'd just like to say thank you very much for coming. I hope you found it enjoyable; not too painful!*

It was nice to talk actually about it. It is probably the most I have talked about it to somebody in a long time, apart from Jane my hearing therapist, you know. It does you good anyway.

*Thank you very much for the work you have done. I am going to stop the interview now. Thank you.*

[End of recording]