



Unheard Voices: interviews with deafened people

Trevor Harwood Interviewed by Colin Ellis

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IMPORTANT

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Interview Summary Sheet			
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[Track 1]

This is Colin Ellis interviewing Trevor Harwood on Friday, 13th March for Unheard Voices Project in Bristol. We are assisted today by the Palantypist Georgina Ford from Wolverhampton. Trevor, would you like to tell us your full name, when and where you were born and about your family, your mother and father, any brothers or siblings and where they came from?

My name is Trevor Harwood. I was born in South London, a place called Merton on 13th July 1955. It was quite a famous day or infamous day because on that day the last woman to be hung, Ruth Ellis, was executed. I was born into my family consisted of an elder brother. My father was from South London, my mother from Yorkshire and we lived in Wimbledon for about the first 5 or 6 years of my life. I don't have too many recollections of Wimbledon except that at the bottom of our road we lived in a road called Engerdine Street was Wimbledon Park and on the far side of the park was the famous Wimbledon tennis club. In about 1961/62, we moved to Leeds up in Yorkshire. Not too certain why we actually moved except it was from that neck of the woods that my mother was born and brought up in a place called Ackworth near Pontefract. We lived in a suburb of Leeds called cross gates and I remember going to two different schools or three different schools there and my recollections are that it was quite a rough area. You had to have your wits about you as a young kid. Older boys would pick on you and in a lot of ways it wasn't the best place, but Leeds did introduce me to my main sort of interest, I suppose, which is football and I went to a school there called Foxwood where our form teacher was also the school sort of sports master, very sporty chap, and we ended up playing for the school football team and we ended up getting free tickets for Leeds United Football Club. Leeds at that time were emerging as the best football team in the country and I suppose that's how I became hooked. In 1968, my Dad got a transfer with his work to Exeter. It came as quite a shock; Exeter wasn't the best known place. Again, probably famous for its bypass and its traffic queues for people wanting to get down to Cornwall for their summer holidays. Leeds United were riding top of the first division at the time, Exeter City were 91st in the football league. I didn't pass my 11 plus but because I did quite well at secondary school in Leeds Mum and Dad were able to get me into a grammar school in Exeter called Heles HELES. Unfortunately I was a little bit behind with my learning because I'd gone to a different type of school for the first year and a half of my sort of senior education and, to be honest, I struggled quite a bit at school. But my main

memory of Heles School is it was a rugby school. So we had two terms of rugby, no terms of football and one term of cricket. That didn't go down to well. But I did meet some people there of my own age and slightly older who had become my life long friends and they have stood by me through thick and thin.

[05:33]

Do you know what your parents' occupation was?

My father worked thought Inland Revenue in Exeter. He was a tax inspector, used to go to businesses around Devon and Cornwall inspecting their books, making certain they were paying the right amount of tax and National Insurance. My Mum had a number of jobs in Exeter, worked in a sweet shop, worked at a local sort of dairy where they sold milk and cheese and stuff. Also she did a bit of rent collecting as well in those days when somebody would knock on the door and cash would be handed over.

Have you any recollections about your grandparents and your family background and what they did or where they came from?

On my father's side, my grandmother died when I was about three or four and I never really sort of got to know her at all. My grandfather on my father's side, like my father in his early years, was in the army and I think my father's side of the family were very much army orientated. My father was brought up in his younger years in India because my grandfather was stationed over there. My father had one brother, brother Jack. On my mother's side, my grandfather was a miner, worked down the pit in Ackworth for many years. I remember him quite well and I think I got my sporting interests from him. On a Saturday he would have the television on with horse racing on, he would have the radio on, either have football on or it would have horse racing and he used to go and watch rugby football club. My grandfather was a very kind chap from what I remember but sadly the days in the pit took its toll and he died from a related sort of illness that miners incurred. My grandmother on my mother's side was again a lovely lady. She had a fairly large family, five girls and one boy. Spent a lot of the time obviously bringing them up and afterwards ran a fish and chip shop in Ackworth for quite a few years.

[08:53]

What was your first experiences of employment and did you have any Further Education to do?

After I left heal school in 1971, I spent a couple of weeks in the summer holidays working at the Corona soft drinks factory in Exeter down by the river. I really enjoyed the experience. It was quite a noisy atmosphere with lots of bottles clanking around. Bottles would come on to a conveyor belt that had previously been used and they would then go through a cleaning process and would then get topped up with new fizzy drinks and then offloaded, put on to lorries and away to various shops. My wage was 22 and a half pence an hour, which seemed rather a lot at the time. After the summer holidays, I finished at corona I had a year at Exeter college. I hadn't done that well at heals in terms of getting qualifications. I left with only 3 O levels. So I went to college to get some more qualifications. I previously applied to join a bank but unfortunately my lack of qualifications didn't allow me entry so I went to college and studied hard in an environment I was more suited to and gained a further four O levels. During my time at college, I worked some evenings and Saturday lunchtimes in a fish and chip shop which was fortes FORTES in North Street in the middle of Exeter city centre. On my way home on a Saturday, smelling of fish and chips like you do working in a fish and chip, I used to pop into Exeter city football club and watch a game on an afternoon before getting home.

[11:21]

Describe how you first noticed the deterioration of your hearing and your feelings to this about related problems tinnitus, balance, self-esteem and your relationships with girlfriends or wives.

Right. Okay, can I do a little bit of a lead into that, me losing my hearing? Yep, okay. To try to sort of link it in. Right, sorry, can I speak now? Sorry. I was born in 1955, as I said earlier so 2005 was my 50th year. I was really looking forward to an exciting year and doing lots of new things. It started off really, really well because my local football team Exeter City were drawn away at Manchester United in the third round of the FA Cup and miraculously got a nil-nil draw. The money generated from that game and the replay has subsequent put my

football club into a sound financial position, unlike many others of today. After that we had a week's holiday in Shropshire, we went to Portugal for a week and as a special surprise my wife Sue got two tickets for the Wimbledon finals weekend, Wimbledon being the place I was brought up in my very early years. I'd also planned a 50th birthday party where I asked for and got -- sorry, I've just made a bit of a mess there. My 50th birthday was on 13th July 2005 which was a Wednesday and the following Saturday I had a party. It was called Trevor's top 50 and at one of the local clubs in Dorchester where I'm now living the look DJ played my top 50 favourite records. The party was a great success and I really enjoyed it. The following weekend, we had a family celebration for my 50th birthday but sadly the following day, which was 24th July, I woke up, got out of bed and nearly fell over and that was the start of the problems that I now have. It was as though I'd had far too much to drink but I hadn't been drinking. It was a really strange experience. I really just couldn't walk anywhere in a straight line and I was hanging on to things as I moved around the house. The following day, I went to the doctor because I knew something wasn't right and my main doctor was on holiday so I saw a locum and the locum thought I probably had an ear infection so I was given some antibiotics. I wasn't well and things didn't improve with the antibiotics so I went back a couple of weeks later and saw another locum. This doctor felt that I ought to have my ears syringed so we put a date for this to happen and I went away with instructions to put drops in my ears to relieve the wax. I think at this time, which was early in the August, I felt I wasn't hearing too well and was looking forward to having my ears syringed so that this would improve but sadly when I had that done, my hearing was exactly the same but had continued to deteriorate and it was becoming quite scary for me. I eventually got to see my own doctor in early September 2005 at which time I was virtually deaf in both ears. I couldn't hold a conversation with anybody. It was a real struggle and it was quite frightening. My doctor within about two or three minutes said, "I've got to get you to see an ENT consultant. Are you prepared to go private?" That was on the Wednesday. We said yes and on the Friday we had a meeting at the local private hospital in Dorchester at the Winterbourne hospital. I could barely walk as we entered the hospital. I was all over the place. My balance had completely gone. The chappy was having a conversation with me I shouldn't hear what he was saying. Thank goodness my wife Sue was with me. I think I was only in there about ten minutes. It cost me £125 but it's probably the best £125 I've spent. The doctor we saw immediately admitted me to hospital and I was put on a strong dose of steroids, some inflammatory -- anti-inflammatory tablets and probably other things as well.

[18:31]

Okay I was in hospital for a week and I remember being in a 2 bed room with a young chap and the young chap had had some problems with his throat and had had an operation and there were, I think, a few complications with it. It was a really difficult time. I didn't know what was happening to me. People were coming and talking to me, I couldn't tell what they were saying to me. But throughout all this, my wife Sue was absolutely brilliant. Sue within a dot of an i had become deaf aware like really nobody else has. Sue knew that I couldn't hear anything so she brought in notepad and pen and would write everything down that the doctors were saying to me. I was very lucky in hospital because during my working days in Weymouth at Weymouth and Portland Borough Council I had met a girl called Julie and Julie had trained previously as a nurse in London but for whatever reason ended up in Weymouth at the local council like me. But she'd packed the council in and retrained as a nurse and lo and behold there she was working in the ENT department. It was a friendly face at a very difficult time. The nurses were really, really good to me and have been through the last three or four years in the number of stays I've had in hospital due to other medical problems.

How did this affect you personally, your self-esteem and your relationship to Sue? Can you remember?

I got ... yeah I got some thoughts on what to say.

Say it.

Right, illness is a funny thing. It's never really happened to me before. I've been ill, like everybody's been ill, but I've always had the type of illnesses where you recover within a week or two. But this was different. Losing your hearing, not being able to stand up, balance has gone, tinnitus had developed, this was very serious and the sort of thing that shouldn't be happening to me. As I said before, it was quite scary and I began to think how life would be if my hearing didn't return. I think in my heart I've always thought that my hearing would come back but, as time progresses, you know in your mind that it won't. It had only been a few weeks earlier that I had been listening to my top 50 records and now I couldn't really distinguish one from another. My wife Sue was there when I needed her.

Sue knew that right from the beginning because the doctors had said that my hearing wouldn't come back and Sue being Sue reacted in a really positive way. She kept saying to me we'll get through this, we'll be all right, what you've got is a life-changing condition not a life-threatening condition.

[24:10]

What do you think, Trevor, contributed to this happening in your life or was it something hereditary through your family? Did somebody else have hearing problems?

Hearing loss hasn't occurred as far as I'm aware in any of my relations so it was quite odd what happened to me. Sudden hearing loss, don't really know what had caused it the doctors say. It's quite rare but it happens. However, in the months ahead we were to learn a lot more about what has probably caused my hearing loss. In April 2006, I developed rather sharp pains in the right-hand side of my body approximately where the appendix is and I'm thinking to myself that's all I need now, problems with my appendix. We went up the hospital one Sunday morning, it was St George's Day, 23rd April 2006, and we saw a doctor in the emergency admission clinic. He had a little feel around my appendix area and, boy, was I jumping. So I got admitted to hospital and they said to me we're going to have to have a look Trey, we're going to have to open you up and if it's not your appendix then we'll have a look around and see what else we can find. So about five hours later, I woke up. It wasn't my appendix. I subsequently learnt that people of 50 don't normally have problems with their appendix. If you have got an appendix problem it's normally in your 20s or thirties. I think they knew it wasn't my appendix and what happened to me was they found a tumour on my bowel which they removed but fortunately for me were able to sew me back up so I didn't have to have a bag at that stage. What I did have though was bowel cancer and following the operation and a few weeks recovery, I learnt that the bowel cancer had not spread to other vital organs, of which I was most thankful, but there were signs of it getting into my lymphatic system. So for the next three months there I was on chemotherapy, being quite jolly to start with but by the time the treatment came to an end in the September 2006 it had really got into my system and I was feeling quite tired by it and quite pleased to be coming off the treatment at the end of the day.

[28:31]

When I left hospital with my hearing problems, I was very fortunate in that the audiologist at Dorchester hospital took me under her wing and talked to me at length about hearing loss, balance problems, tinnitus and about all the support there are for people who acquire these problems. She also fitted me up with my first hearing aid, a digital hearing aid in my left ear which proved to be a great improvement for me. In the January of 2006, my hearing in my left ear suddenly disappeared and even with the aid of a hearing aid I couldn't hear anything in my left ear. So my audiologist switched my hearing aid to my right ear, which had recovered slightly in the preceding few months. She thought it was quite odd that this should happen and that she hadn't really come across it before and also at this time my hearing was fluctuating. Some days I could hear really quite well with a hearing aid and other days I really struggled with it. We talked to the ENT consultant, a Mr O'Donnell, and because Dorchester is a fairly small hospital and what had happened to me was quite unusual, they agreed to refer me to the National Hospital in London at Queen's Square. I was due to go in April 2006 but unfortunately the appointment coincided with my second admission to hospital for my bowel cancer operation. So we ended up going up to London in June time. There we saw a Professor Luxon LUXON and Professor Luxon got me to or undertook a number of tests to do with my balance and my hearing. It turns out the test she did on my balance had shown that my balance functionality in both ears had, I think in her words, been destroyed. It had gone completely and it was therefore no surprise that I couldn't stand up. She undertook a number of tests to do with my hearing, got me to walk up and down, twisted my head from side to side, and at the end of the day she said that she wanted me to go and see a specialist in Hammersmith. Professor Haskard HASKARD at Hammersmith Hospital is an expert in the immune system and tends to deal with the people with rheumatoid arthritis and we got to see him a few months later. He took some blood tests, had a chat to me about my problems and subsequently reported that I have all the characteristics of an auto immune disease, which he termed auto immune inner ear disease where the immune system has attacked the inner ear and by attacking the inner ear it has destroyed the cells which produce both the hearing mechanism or support the hearing mechanism in the cochlear and also in the semi-circular canals which provide you with your balance function.

[34:00]

What was the reaction to your friends and work colleagues knowing that you had gone through a very rough patch and lost your hearing and was your employer able to help you?

The reaction was what you'd ever hoped it would be. Everybody rallied round to help me. My friends all came to see me, my work colleagues came to see me, my manager came to see me and my manager's manager also came to see me. Every five minutes people were popping in the door, coming to see me, asking how I was, asking if there's anything they can do to help me. It was a very difficult time for me but everybody was there for me and nobody shied away. So I look at what happened to me -- well, I look that I was very fortunate in what happened to me because I know that other people who have gone through what I have gone through do become isolated. But more me, I was very lucky.

Trevor, who recommended LINK to you and did they help you and Sue?

My audiologist at Dorchester hospital suggested that I might like to attend lipreading classes and gave me the name and address of the local group. Sue phoned up the lipreading tutor, a lady called Maggs, MAGGS, and we attended, Sue and myself we attended the first lipreading class on 4th October 2005. I remember the date because it was our 19th wedding anniversary – not the way that we had planned to spend our wedding anniversary but there you go. At the lipreading class I met a lady called Liz. Liz had lost her hearing over the preceding ten years to a level which was very difficult for her. But Liz had been on a LINK course and had been so enlightened by what LINK had provided for her in terms of strategies to cope with her hearing problems and hope for the future that she recommended that Sue and myself also attend such a course. When we next saw our audiologist, we asked about the LINK course but barriers were immediately sort of thrown up. You've got too much hearing to be able to be recommended for a LINK course I think was one argument. We think another argument was the funding that would have to be provided by the local Health Service. Sadly for us, we were blocked, I believe, at a time when LINK would really have helped us in those early months following my hearing loss from attending a LINK course. But we persevered and in the March 2007 funding eventually became available and we attended the LINK course. By this time, we had learnt quite a lot about hearing loss and strategies of how to cope. Sue had been instrumental in obtaining as much information as possible about how we needed to adapt our lives to cope. But LINK, nevertheless, added to our knowledge and most importantly we met people who had suffered like we had suffered and on a number of

occasions had suffered a lot more than us. We made some good friends at LINK who we are still in touch with today and we feel that LINK is a vital product for anybody who has found themselves in a deafened situation but I think local authorities or Health Services must switch on to the fact of providing help as soon as possible after the event because that's when people need it most.

[40:33]

Trevor, would you like to tell us how the impact of deafness, of your illness affected your social life, your hobbies with football obviously, whether you were able or with comfort to go see the Grecians in Exeter alone or did Sue have to take you?

Well, of course my deafness, my balance problems, my tinnitus, my bowel cancer have all had an effect on my social life. However, from the beginning I was told that although my deafness will never return to its natural state, there are things that can be done to improve your balance. It has taken quite a while, probably three years, but I have undertaken a lot of exercises, I've had a lot of determination to improve my balance and I can now say that my balance has been retrained and I feel that I am walking, running, as well as I would have hoped for three years ago. For two years it was a real struggle. As well as having the balance problems, I'd also through the effects on my inner ear balance mechanism had difficulties with what is known as gaze. This is where when you walk everything in front of you moves around. I think there's a link between the balance mechanism in your inner ear and your eyes that keep things for normal people into sort of focus but for me this link had been broken and, therefore, there was like a delay from causing this gaze problem. My main hobby, I think I've already touched on believe it or not is football. I've always played it, watched it, talked it, and all of a sudden I can't kick a ball any more. But by retraining yourself to balance by doing the exercises that you need to do, I have learnt not only to walk but I can kick a ball now, I am back playing kick around football twice a week and I'm also able now to ride my bike again. My other main hobby has been music. I've always enjoyed rock music, folk music, most sorts of popular music. But listening to music with a severe hearing loss has become very difficult indeed, to the point where I tend to switch off now and not try and hear music. It was very upsetting when I first suffered my hearing loss but I can still remember the tunes in my head so I've still got the memory there. And, therefore, music still forms a part of my life but not like it used to.

One of the other problems that hearing loss brings is that you can't enjoy instant humour any more. Quite often in comedy situations, for example, where somebody's telling a joke their voice will change just when the punch line's being delivered and no matter how hard you concentrate on following the joke or the story, I always seem to miss the vital ending. I used to like watching comedy programmes on the telly. I now watch television with subtitles but it's difficult to watch what's happening on the screen and reading the subtitles at the same time. For documentaries it's not so bad but for comedy where you get that visual effect linked with the verbal, it is very difficult to follow and be impulsive like I was before.

[48:38]

Trevor, did you find that there was prejudice or discrimination that you encountered when you went into shops or parties or anything that people would shun you?

No, not really. I don't really think anybody has shunned me as such and I can't say that I've really come across prejudice or discrimination because of my hearing loss. I have come across situations whereby people don't understand the problems I have with hearing loss but I seem to have adopted the stance whereby I'm the one with the disability so therefore I'm the one that should make allowances whereas some other people would say I have a disability, therefore you need to make allowances. So often when come into situations and people don't really react the way I need them to react because of my hearing loss, I don't get upset about it, I try and explain my situation to them and ask them to repeat things or to maybe explain things in a different way so that I can follow what's being said.

[50:22]

Did it affect you in your own transport driving or if you had to travel on a bus or even get on railways, did you find trouble?

For the first year of my illness I didn't drive. It was mainly because of the problem I had with my gaze where things were bobbing up and down in front of me. I felt I wasn't safe to drive. But nobody actually said you can't drive and nobody took my licence away. After about a year I felt things had settled down a bit so I got behind the wheel, drove a couple of miles, felt quite comfortable and built up my driving from there. After about six weeks or so, Kim who

lives up the road from me who's a driving instructor for the police, took me out to see whether he felt I was safe on the road. He gave me the okay and I've been driving ever since. Some people have said that if you're deaf and driving then you've got no distractions and, therefore, you're probably a safer driver. I'm not so sure because if you're able to hear what's going on around you, you probably are more aware. But I don't think my hearing disability affects my ability to drive at all and anybody who is deaf should not be put off driving. As for public transport, I have found this a bit difficult at times but I tend to travel by train to London with Sue. Sue hears everything that's going on and therefore keeps me in touch with any announcements.

Were you able to get local Social Services support or help and advice about benefits and were you aware of the access to them and the things to help you in the home like fire services or door bells?

What we've discovered is that there's a huge amount of help out there for people who are deafened and people who have had cancer like I have. Social Services were there for us but we had to approach them. They provided us with some initial hearing aids to help with the television. I am registered with Social Services, I am registered as deaf ... stop a minute. I heard -- I was encouraged to approach Social Services through the lipreading tutor. The lipreading is quite proactive in informing the class about the benefits that deafened people can obtain. By registering with Social Services, it means that you become a number. Deafened people need funding in terms of so that facilities can be provided to them. Unless deafened people get themselves registered, the authorities don't have the numbers in order to obtain funding to provide services. Other things that we've benefited from is we've had a fire alarm system put in by the local Fire Service. That was provided free of charge. And also through work I've been able to obtain some funding from what's called Access to Work to provide me with some tools and equipment such as a telephone, and a portable loop-system. The funding that I received through Access to Work has helped me greatly in my day-to-day life in the office Weymouth and Portland Borough Council it has enabled me to participate in meetings by having the portable loop-system and also enabled me to speak to people on the telephone. My hearing, however, at the time of this session is not as good as it has been and I feel I must now go back to the Access to Work people and approach them again for further help such as I've forgotten the name of it ... text phone -- such as a text phone.

Trevor, what do you think the future holds? Do you believe that you've achieved everything to give you a better life with your disabilities?

I think when I look back over the last three and a half years I can't believe how great a progress I've made. I'm able to walk in a straight line again, I'm able to kick a football again, I can ride my bike again, I can hear to a degree although I'm not satisfied really with my level of hearing but I do feel that I've achieved a huge amount. My lipreading is a bit intermittent. I go every week to lipreading classes. They have been a huge help to me. The lipreading tutor I can lipread really well but then when you turn and speak to other colleagues in the lipreading class it's not so easy. But lipreading's been another lifeline like so many other things have over the last few years and I'll continue to support that class in the knowledge that if all else fails, if I can lipread then I can continue to fulfil my life to its full.

Trevor, you and Sue obviously receive great support from the charity LINK and it was lovely to see you at the conference, both of you, and you know that the time has moved on and Hearing Concern has now joined LINK. They do an awful lot of work with fund-raising, volunteers, programmes to help families etc. Would you consider taking a more active role knowing that the Olympics will be down in Weymouth and the Paralympics will be following them afterwards when we will have disabled people?

I've spent the last three and a half years trying to get my life back together and I feel I've succeeded in that to a great degree. Whilst I'm in full-time employment, it is difficult to spend time supporting organisations but I do recognise that I need and wish to give back to people who have supported my time and effort to help them continue the great work that they do for the deafened community. I think the Olympics coming to Weymouth is really exciting. I'm really looking forward to it. I think it would be a good opportunity for me to put myself forward in any way that I can to help people who are deafened enjoy the Olympics to a greater degree than they would otherwise, especially as the Olympics are on my doorstep.

You may feel that talking to Weymouth Borough Council and just casually discussing the future of the Olympics coming and your disability that they may put you forward as they will have an input, if you like, in networking with the organisers etc.

I haven't thought too much about this to be perfectly honest. I think as time ticks on and the Olympics approaches there will be a greater link to the decision-makers within the council and the other organisations for support workers. So maybe in the months ahead this is something I need to be mindful about and I think if the time is right for me then I will offer my services.

[01:02:07]

Should a friend in your employment, a neighbour, one of the family or somebody strange come to tell you that they too have lost their hearing, what experiences in life and being deafened would you recommend to them to help them?

Losing your hearing can be a very isolating experience but for me it's actually opened my eyes to the greater world. I think maybe before I lost my hearing I was a bit naive as to how life was for a lot of people in the community but now I know that people with disabilities have a difficult time. So if somebody came to me and said, "I've lost my hearing" whilst this can be quite a devastating experience, it is not the end of the world. There's a lot of help out there for people but you have to be prepared to go out and seek it. The first thing you have to do I think is yourself accept maybe what's happened to you and that's easier to say than done. So I would say to that person seek as much help as you can. This may involve somebody writing information down for you initially so that you are aware of what is being said or aware of what you need to do or aware of where you need to go. You need to get yourself a good GP, a great audiologist, a sympathetic ENT consultant. You need to join clubs such as lipreading club or any other deafened association that may be near to where you live. By mixing with other people who have experienced what you are now experiencing, you will soon realise that you are not alone. The RNID say there are 1 in 7 people have a hearing loss. That's a large percentage of the population. The number of people seeking help through hearing loss is increasing and the amount of research and funding going into improving people's well-being who have become deafened is enormous. It is important that you tap into that resource and obtain the support and benefit that you need in order to make your life manageable again. It can be done, it will take time, it will be an effort for you, it will be quite emotional at times, but you will get through it and you will be surprised at the amount of help there is out there. Organisations such as LINK or Hearing Concern LINK as they are now

called will continue to support all deafened adults and will continue to support all deafened adults so it is important that you join these organisations, receive their regular updates and attend their annual conferences in order to take advantage of everything that's available. The most important thing though is to have a strong, caring family, friends, work colleagues, community around you to get you through this difficult time. I've been particularly lucky. Unfortunately I know others haven't. But if you can get these people to help you in every way possible, then should you lose your hearing life will be -- you will be able to tolerate life and get a good quality of life at the end of the day.

Well, Trevor I want to thank you very much for this very interesting story.

[End of recording]