



Unheard Voices: interviews with deafened people

Jane Atkinson
Interviewed by Vivienne Keightley

British Library ref. C1345/63

IMPORTANT

This transcript was created at the time of the interview by a Speech-to-Text Reporter. The summaries were completed by the interviewer after the interview using the STTR transcript.

Every effort is made to ensure the accuracy of this transcript, however no transcript is an exact translation of the spoken word, and this document is intended to be a guide to the original recording, not replace it. Should you find any errors please inform the Oral History curators

Oral History
The British Library
96 Euston Road
London
NW1 2DB

T: +44 (0)20 7412 7404
E: oralhistory@bl.uk

This interview and transcript is accessible via <http://sounds.bl.uk>.

© Hearing Link. Please refer to the Oral History curators at the British Library prior to any publication or broadcast from this document.

Interview Summary Sheet

Ref no: C1345/63

Collection title: Unheard Voices: interviews with deafened people

Interviewee's surname: Atkinson

Title:

Interviewee's forename: Jane

Sex: Female

Occupation: Outreach co-ordinator for Durham deafened support

Date and place of birth: 1949

Date(s) of recording: 21st June 2009

Location of interview: Holiday Inn, Washington, Tyne and Wear

Name of interviewer: Vivienne Keightley

Speech to Text reporter: Julia Jacobie

Type of recorder: Marantz PMD660 on compact flash

Recording format : WAV 16 bit 44.1 kHz

Total no. of tracks: 1 **Mono or stereo:** stereo

Total Duration: 1 hr. 23 min.

Additional material:

Copyright/Clearance: Open. © Hearing Link

Interviewer's comments:

[Track 1]

This is Vivienne Keightley interviewing Jane Atkinson on Sunday the 21st June 2009 for the unheard voices project at Washington, Newcastle. The Speech to Text Reporter is Julia Jacobie. Just to get us started Jane, can you confirm for me your name, your maiden name, date of birth, and occupation please.

My name is Jane Atkinson, my date of birth is 5th of October 1949. My maiden name is Burlingson. My occupation is outreach co-ordinator for Durham deafened support.

Thank you. Can you tell us a little about your mother and fathers occupations?

My father was a miner all his life in the coalfield mines of Durham he worked in Horden colliery mine for all his working life, until he had to retire at the age of 60 with emphysema which was a legacy of the mines. As well as hearing loss. My father did have a hearing loss, but it was through industrial deafness. My mother as all women in those days was a housewife and looked after the husband and family. She didn't work at all, but did various voluntary jobs. Mostly for the British Legion, benevolent funds and poppies and things like that.

Did you have any brothers and sisters?

Yes I have one sister, who's 10 years older than me, I had a brother who was 5 years older than me who died when he was 54, and I have 2 brothers younger than me. One is 55, the other 58.

Can you share any memories with us, just to get us started, of your early childhood and through to school?

I think I had a fairly normal childhood for any child of a working miner, we lived in a colliery house, I think one of the main childhood memories was the coal motor coming dropping a huge tonne of coal in the gate, up and down the street. You couldn't walk down the street for all the piles of coal outside each gate.

I can't remember any outings as such, maybe I think my holidays was to visit my

sister who lived in the Midlands. We didn't, we hadn't all the facilities that there is now, the children in the home I think it was better the way we did, we were safe enough and we were allowed to play outdoors, and enjoy the freedom of outdoor life, and sunshine and in all weathers actually. Playing with friends in the street, it was a major thing after school and weekends. Washing lines drawn across the street, hindering games of cricket and all kinds of things.

What about your school life?

Moderate I would think. I think all my life I have been midway between everything, Jack of all trades, master of none. That's how I see myself. I was really muddled on through school, most of my life. I didn't dislike school, and I didn't like it, it was one of those things that really you had to do and get on with, I think the best time at my school life really was when I left.

[05:32]

What area did you live in as a small child?

I lived in Horden, it's a small village in Easington district in county Durham, very close to the sea. You can see the beach, you could see the beach from my bedroom window. But don't get any misconceptions when I say the beach it was a slurry of coal and pebbles and ash from the coal mining. It wasn't the kind of beach you could go and plodge in.

What area do you live in now, is it the same area?

I still live in Horden although I did move to another village in Easington for 5 years when I was married. I came back to Horden which has not changed much over the years except as much you don't see the washing lines strewn over the streets and the beaches are trying to get it cleaned up, some things have changed a great deal, others haven't.

Sorry I am just catching up on the screen. So you mentioned there that you married, can you tell us a little bit about your husband, and when you got married?

I am thinking, I got married in 1971, my husband's name is Alexander, he gets the nickname Alex. He gets Alex. There's not really, what do you say, that sounds awful doesn't it after nearly 40 years of marriage, what do I say? It was how I met Alex well, Alex had been engaged to someone else for 6 years when I met him, and they were having a time apart from each other, they weren't getting on. And I think I must have put a blotto on that one we met each other and were married a year later. That's it.

Do you have any children Jane?

I have 3 children, Christine is the oldest and I have Donna a girl she's the middle, and Alexander he's the baby. Christine is in Darlington, Donna is in Horden, they are both married with children, Lee is in Norwich he did an art degree in Norwich he loved it and stayed down there.

What about grandparents do you have memories of grandparents as you were growing up?

Memories, my grandparents all died fairly young but did seem to me to be they were old people but when I think back now they were just in their early 60s. One grandmother I can always remember being poorly, we always seemed to -- I hated going there as a child I always had to be quiet, sit on the front step not make a noise because Grandma was poorly. This seemed to be for an eternity, all my life at the time I knew her this was the poorly grandmother. The other grandmother was a lady who was just always there, she was always coming to see us and then suddenly one day she stopped. I was fairly young when I lost both grandparents, one grandfather was very young, early 50s I didn't see much of him at all. The other grandfather died very suddenly as well. Once again early 60s.

What kind of impact did that have on you from the grandparent that was always around suddenly wasn't?

I did think of grandparents as being people you had to do things for and it was people you always had to be good around. I think it was because, I was, my mother was a decent age when she had us younger children, so as I have said my grandparents always seemed to be people who were old and to be looked after. This was always my thing about grandparents. I never had a grandparent really what would take me out, or play with me and things like that.

[11:30]

Okay. We'll move on now from the background. We'll talk a little bit about if you can share your memories of the onset of your hearing loss.

Well I have been deafened now for 12 years and its still, I am fine with it. I cope very, very well until I have to talk about it. I was I wasn't well at the time. I don't know what come first, the heart attacks or the hearing loss but it all happened about the same time. I wasn't feeling well, I was getting breathless, I did feel as though I wasn't hearing very well. I had one hearing-aid which was for just slight to moderate loss. I managed an old person's complex and 60 bungalows, I didn't have a problem with the phones or the intercoms anything at all. But I had left work because of ill health the year before. Arthritis and various other problems. But, when I had the heart attacks, after I was in hospital 3 weeks because there was complications, I was saying 'I can't hear properly, I don't know what's wrong I can't hear very well'. But the staff and my husband were saying, well it's because you're not well. You're lucky to be alive. The staff and the doctors also said we know it's in your notes. Because my husband had said I had a hearing-aid so they thought when I was losing my hearing even more, that this was the norm, this was me the hard-of-hearing person. I couldn't, I tried to explain that it was worse than it had been when I came in, you know I couldn't even hear with my hearing-aid in. It wasn't as I have heard Heather Jackson say about people open their mouths and nothing coming out, I could hear. I could hear some words, sometimes it was just as though they were talking a foreign language I couldn't understand what they were saying at all. And it was so frustrating, and visiting time I would be saying 'will you speak up I can't hear' and they were saying to me 'will you stop shouting', everyone is looking will you stop shouting. And I think that was a major frustration, the stress of that I do believe kept

me in hospital longer than I needed to have been. When I came home from hospital, one of the first jobs was my husband took me to an audiology department. He had to take me in the wheelchair because I still wasn't well enough to walk about. The audiologist was good enough to see me and put me in for a hearing test. They said my hearing had deteriorated drastically. They sent me to a consultant, but when I went to see this doctor, I said 'I am sorry I can't hear'. So he turned to my husband and every word after that was said to my husband. And I kept saying 'I don't know what you are saying', and my husband as well just sat and spoke to this doctor as though I wasn't even there. It was so frustrating. And at the time I didn't feel as though I should say anything. Because this was a doctor. Who was I? When we got into the car park to come home, I said to my husband 'what did he say?' And he said it's obvious you have lost a lot of hearing, you'll probably lose some more, there is nothing much they can do. And that was it. But I wasn't happy with this at all. I asked for an appointment to go back to the audiology department I had seen in the first place, just to talk to him, a hearing therapist anybody, they advised lip reading classes and suggested looking into having a cochlear implant.

Can -- sorry,

No it's alright.

[16:48]

Can I just take you back a little bit you said that you had a hearing loss before you went into the hospital with your heart problems. How did you arrive at that?

I don't know. I had this slight hearing loss, what happened when I went to work in the manager of these homes the complexes when it was starting to answer the intercom, there was some things I was missing. So I thought there's something wrong, I got my husband, I think this machine is muffled some things I don't hear but he could hear it quite well. And it was suggested I go for a hearing test. I got a hearing test and I got a hearing-aid. And it was fine. It was lovely. I used the phone, and really I used the phone then without the hearing-aid, it was just this intercom I couldn't quite catch everything that was said but I had the hearing-aid for 25 years. My hearing never

deteriorated anymore over the 25 years. I could go and get it checked and the mould changed and things like that but there was never anymore deterioration over the years.

So just for the record what age would you be when that first hearing loss was diagnosed?

I was about 29, 30 when I first got the hearing-aid.

Can I take you back again to when you were taken to see the consultant. How did that appointment make you feel?

Well, as though I wasn't worth making the effort for. As though my hearing loss was a triviality to him, something he sees every day and there was nothing he could do therefore it wasn't really worth bothering with, that's how I felt.

So would you say you felt misunderstood by the consultant?

Not really, no I think he understood the problem and I think he knew what was going on, he just ..., he had seen people like me on numerous occasions and I think I was just another one of the many.

So you didn't feel as if you were an important patient

That's it. I didn't think I was very relevant to him at all.

Do you, just looking back now do you think that was actually the case or it was actually how you actually felt?

Looking back now I think it was the case.

[20:12]

That's sad. What about, you mentioned you were sent to audiology for hearing tests, how would you say your other, shall we say, care or support was handled?

Much better. Much better. He was much more considerate, and I think he was much more aware of the affects that such a severe hearing loss had on a person. He sat and he talked to me about it, how they couldn't always explain why this had happened, or how it might get even worse. But he also explained that things that could be done to help.

So was a diagnosis made as to why you lost your hearing?

No never. They think it was the circulations problems at the time. Which caused the heart attacks and everything else. The problem I had been having with my health, just nerve damage.

How did that make you feel not really knowing what had happened?

Well like everything, I think if you can put a name to something you feel better. If people say why have you gone, if I could have said well because I have something and give a name for it you feel it much more accepted.

[22:14]

On a wider sense, talking about anything, your hearing loss how did it change you as a person?

When I first lost my hearing, I felt as though I had lost my identity. I was always very close with my oldest daughter, we used to go shopping, we were friends. But after my hearing loss things changed. She was one of the people I just couldn't understand for some reason. She did try, but I suppose it was frustrating. She had two young children, used to drive from Darlington with the two children, then I was always so hard to communicate with. I suppose miserable and frustrated. I must have cried buckets in the first year. My middle daughter who had always been, she had always had a way of her own, got a very good lip pattern I could lip-read her very, very well but sadly she was the one who always had led her own life and done her own thing who I didn't see much. And of course my son was away in Norwich I couldn't phone

him. My sister was okay. Good lip pattern but I couldn't understand her husband or any of her family so I didn't visit much at all. My husband, well, hearing people have a problem understanding him. He's from the collieries he talks really, really fast, he strings his words together, but over the last 12 years he has slowed down a little bit, he does his best I suppose. I still have not got back the closeness I had with my daughter. My life changed beyond recognition. I have very, very few friends that I had before I was deaf. Even my name changed. When I was christened Jane, my mother was called Jane and hated it. When I got home, from being registered she said right, Jane you will always be called Jean. So up to the time I went deaf I was always called Jean, everyone knew me by Jean Atkinson, until went deaf. And I didn't realise people were calling me Jane which was on my medical notes, and everything else. And when I did find out it didn't matter, so now everyone from after deaf calls me Jane and before deaf calls me Jean.

That's very interesting. You say you struggled at first to understand your husband, how did you get through that as a couple?

Well we made a lot of our own signs up, we didn't get on at first, I think the way I coped with it was just not talking to people so I didn't have to listen. My husband's very much an introvert, I think if he had gone deaf he wouldn't have even noticed, but sadly it had to be me and I was very much a people person. I had always been the one who mixed with people, brought the company to the house, and things like that. And he had always gone along, gone with the flow. He didn't encourage me, at all to get back into life or to mix or anything like that. He found it very, very hard communicating with me. He didn't like having to write things down. I tried really my husband is, is this confidential? My husband is bipolar, I have always been a carer and kept lives easy as possibly for him. This was the same as my deafness. I felt as though really, I couldn't mourn my hearing loss as I should because I had to keep this facade of coping alright. At the LINK Centre my husband even said my hearing loss had not bothered him much.

Would you like to stop? I will just give you a minute.

I am alright.

That must have been a hard thing to hear.

It was yeah.

Are you okay? Would you like me to stop the tape for a few seconds?

No I am alright thank you I am fine.

[29:41]

What practical support were you receiving at this time? You mentioned hearing-aids at one point, did you have any other equipment to help?

I had nothing at all. After about nine months, my daughter got in touch with social services. A social worker came out who was new to the area, and new to social work actually. Although she was very sympathetic there was nothing at all she could do. I wasn't able to use, she tried the loop system and tried amplified phone but I couldn't understand. Even her talking I had my daughter had to translate what she was saying some of the time. Loop hearing-aids were no good. I had seen about a cochlear implant, but I wasn't, I couldn't have one at the time because of my health problems.

What about your social life?

Ooh, well it was non-existent. That was it. We didn't go out at all. My husband didn't, neither of us drink well very, very little. We have never gone to pubs and clubs but we used to enjoy going out for a meal. But that is when you have got a deaf wife you go out, there's not much conversation. We used to go and have the meal and come straight back home. So what used to be a two or three hour evening, ended up an hour if that. We'll have the meal and straight home.

[31:58]

You mentioned that you now have a cochlear implant, can you talk us through the process of that?

When I first went to be assessed for the cochlear implant, they said I was eligible for one but because of the health problems it was advisable to wait. I went back, two years later and after health checks they said I could go ahead with the cochlear implant. But even then I felt as though I had been pushed into it. When I went, when I mentioned that I might be eligible for a cochlear implant, my family were all delighted. It would be so much easier to communicate with me, my husband was things will get back to normal, and I felt as though I was doing this for them. And once again I felt as though that everything had just gone over my head, and I was just carried along with it. So a time came when I said right that's, I need to hang on here and take stock, I really want this cochlear implant? I had just learned to cope with my hearing loss and got used to being deaf. I had got friends who were deafened who understood, we had a small support group. And if it didn't work I would feel as though I had gone right back to square one. But after the initial assessment when the letter came to say give me a date for the implant, I didn't think twice about it. This was what I wanted to do. So I went in and I had a cochlear implant. Although I told everyone I would have this operation but it wouldn't make me hearing, I wouldn't have any hearing at all for a month, not even the sounds that I had, I wouldn't have nothing at all. But when I came home everyone said 'can you hear now'? It was ... the month obviously with no hearing went over okay, we struggled a bit more than the norm but okay. When I was switched on, I couldn't believe it. My husband said 'can you hear'? His mouth opened but nothing came out. And then seconds later, the sound like a Dalek. The sound and the mouth movement didn't come together at all. The audiologist spoke he was exactly the same. I was told this would improve. On the way home in the car, I had to ask my husband to stop three times I couldn't stand the row. It sounded like someone jumping on bubble wrap but it was the sound of the gravel on the road. And to hear the birds sing, I have prayed to hear the birds sing but when I did if I had a gun I would have shot them, they sounded like dogs barking. It was awful. Really bad. Everyone sounded exactly the same. My 3 year old grandson sounded like his Grandad. My daughter sounded like her husband. And everyone had this awful echo drony sound to it. But a the days and the weeks went by, things became as I remember I could recognise speech, and everyone sounded as

they did. Except me it took 3 months before my voice sounded as I remember it. My grandchildren called it the magic magnet. Because once I stuck it on my head I could hear. It was magic to me.

[37:19]

Are you happy that you have the implant now?

Well it's not magic. And I am happy I could never ever have managed without it. I couldn't honestly see going on the way I did, with no hearing. If I had gone deaf in my teens it might have been better, but nearly 50, and health problem it was a struggle. It's not perfect, but its good. It helps. The only obstacle is that people think you have a cochlear implant, so you can hear. My implant now, the internal part of my implant is not working properly so it is going to be removed. And I am going to have an updated one put in.

How do you feel about that operation coming up?

Well, I am not very happy about the operation, but I am excited about having a new state of the art cochlear implant, but obviously with the health problems I have got any operation is more of a risk. I have had a stroke I have had a couple of heart attacks, I am diabetic so its a risk. Every operation is a risk but it's worth taking.

For the record can I just ask the year you had your implant?

Yes I had my implant in 1982. Sorry no ... no 1982 no I didn't I had it in ...

Would you like me to pause for a minute. Can you confirm the year that you had your cochlear implant?

Yes I had my cochlear implant in 2002.

So how many years have you been deafened?

I have been deafened for 12 years.

[40:06]

Can I ask about any employment during this time? How did your hearing loss affect that?

I was already retired from my job as manager of a housing complex, because of other health problems. I used to do voluntary work and things like that but I had to stop because I couldn't hear the phone, and things, obvious things attached to deafness. I had set up in my home a small, well it was only three or four or us, group for people who the social worker had met and introduced me to people like myself who had fallen through the cracks in the system.

Before we go into a break, can I just ask any are there any particular defining moments, good or bad?

Since deafness or since I have been deaf?

Since your hearing loss?

I think having a cochlear implant was one of them. Meeting Heather Jackson at the LINK, the rehabilitation week was another. Lots of smaller things that happened within county Durham that these are personal achievements and achievements for the organisation that I set up. I received a millennium award, I recently received a Heather Jackson award for the work I have done with deafened people. As you see all these things related round deafened and the support of deafened people which really is my main thing.

We'll go into a break now.

[43:05]

If I can just take you back you mentioned the Link Centre. Can you explain to us the time at the LINK centre please?

I don't know how to start off really. What, I had asked the consultant if he would refer me to LINK as I had spoken to someone who'd been there and he strongly recommended it. And I didn't know what to expect, I didn't think they could do anything at all to help. But my husband and I went along, and the whole week was really a godsend. I think the only thing wrong for me with that, wrong for us with that week really was that I was told it was usually 5 or 6 couples. But my husband and I were the only couples that week. The others were single people with friends or whatever. But it was still a very rewarding week. It was at LINK where I learned about palantype I had never ever seen it before. Although I had been working in the community now for a year banging the drum about deafened people and ways forward and equal access, there was this marvellous thing that we'd never heard of, never seen before. Everyone was included. There was no-one left sitting left to milk because they couldn't understand what was being said. An amazing lady called Heather Jackson came one day to give a talk. And she spoke about how deafness had changed her life, all the trauma that she had gone through, the heartache and how it had changed the lives of her family as well. But she had got over it. And had moved on. And that to me that's what that LINK week did. It helped us not just to accept my hearing loss, but showed us ways to move on and it proved that there really was a life after deaf.

Can you expand a little bit on the other things you covered during the LINK week?

Well we, I had already been doing lipreading, classes at home, but there was a lady coming and spoke about the benefits of lipreading, someone come to talk about balance problems, which was another thing that I had problems with. And tinnitus, all things related to hearing loss. The thing is that they realise to that everyone was different, and just because we were deaf didn't say that we all had tinnitus or we all had balance problems but some of us did. Everyone is individuals. And we I was there as Jane Atkinson not Jane the deaf person.

How did it feel to meet other deafened people?

It was good to meet people who were deafened the same as me, I think it did my husband good to realise that I was doing better than some of them at coping. Because he could, he just couldn't understand why it was harder for me to hear than it was for other people with hearing-aids in. So he learnt then the difference really that was where he learning the difference between hard-of-hearing and deafened.

[48:14]

Do you think your husband learned things to help himself?

Well I think my husband learned that he wasn't having such a raw deal. And that working together we really could get through this. It was easier for him if he learned to speak clearly, and remembered to look at me when he was speaking, all these kind of things. He learned that conversation really is a two-way thing. And we did get on much better, things were much easier at home when we came back.

Can I ask do you think you have learned anything about your husband's perception of your hearing loss?

Well I think my husband's perception of hearing loss is the same as the majority of hearing people's, and it has learnt me a great deal now when I am going to visit other deafened people because I can relate to how their partners feel because of the way my husband was.

[50:07]

Right. Can I just take you back to something you said at the beginning of the interview, that a parent had a hearing loss. Do you think that helped you in anyway? That knowledge?

Not really no because I think it was worse because he had a hearing-aid in and he was hard-of-hearing. So they couldn't understand why I just didn't put my hearing aid in

and hear as well as he had. My father until the day he died thought I was just over-reacting. And I just had to learn to get on with it and wear the hearing-aid.

[51:02]

Can you talk a little bit about the work you do now with other deafened people?

Well, here in East Durham when I lost my hearing there wasn't even a lip-reading class, nothing at all was available. So 3 people who the social worker had introduced me to, met and started a small group. Initially started in my home. I put in for funding, hundreds of letters but of course most were turned down because there was a hard-of-hearing group and a deaf club in the area. There was no room for another one. It was, I asked funders to come and meet me and talk about the problems that we were having. One person did from Northern Rock Foundation. And it was from them we were given our first grant, £300. Paid for lipreading for a few weeks. After this we received numerous other grants which helped us to keep the lipreading teacher. End we moved into a room in a community centre. We had this group sessions one day a week, but I was soon getting messages and e-mails from people right across Easington and Durham, people who had felt left out because they didn't fit into a hard-of-hearing club. And for obvious reasons, were excluded from a deaf club. I would go to meet people in their homes, work with families, showing them communication support, helping them to understand the problems associated with acquired hearing loss. I would sometimes learn the family basic sign, so it was something they could do together. Usually something they are doing together for the first time in a long time. I would learn clear speech, I would have all the members of the family put hearing-aids in and have a wireless going to help them understand what it's like. I would sensitise the need to heads of schools, where deafened people had children. So they weren't having to go into big noisy halls, try and accommodate them. As always the deafened people never asked for what they need because they don't know. We went, this small group moved from, we moved on to Shotton Colliery where we set up another group which was also on every week. At the time I was given a millennium award, this helped me to get training, to move the organisation on further. I did training on chairing meetings, funding applications, constitutions, all the politics that go with running an organisation.

We got funding, oh sorry, we got funding for an office manager and an office in Lee House in Peterlee. And set up another 5 support groups throughout the county. The 7 support groups now run weekly with lipreading teachers there every week. I meet people in their homes, help them to gain confidence and bring back self-esteem, and gradually introduce them to the support groups. Once they are in the support groups I step back and leave them in the group, but I am always there if they need one-to-one support. I am contacted through the office and still see at least 3 people a week from the groups. We help people with Access to Work, welfare rights, all kinds of things everything associated with hearing loss really. I work very closely with the sensory support team in Durham, and the audiology department in Durham and Hartlepool. One of our lip-reading teachers is an audiologist from Newcastle hospital. She also does tinnitus support. We recently acquired funding from Durham NHS, to support our 7 support groups. A tinnitus support network throughout the county, and support for another two ‘dealing with deafness weeks. These are 2 weeks where I learned from LINK that people find it much easier to come together in the early stages of hearing loss. But one thing I did find that when I came home from LINK, if we had not had the small support group, I would have been still out on a limb. Here in Durham we have this small, non residential rehab weeks, and people continue the support both one-to-one and in weekly groups. Until the need is ended, well forever.

[59:10]

How does that feel to be offering all this support to deafened people?

Well you won't believe this but frustrated because I still feel as though we have touched the tip of the iceberg. And I still, I am asked to meetings, there's no Palantype. Or they have apologised when I have got there and said there was no Palantype available. But I have asked them ‘would you have dreamt of having this meeting if there was no ramp for a wheelchair’? You would make sure there was a ramp for a wheelchair, before you arranged the meeting. Communication support should be in place before a meeting is even thought about. I am like a dripping tap in Durham.

Can you just explain for the tape, what Palantype is?

Palantype is like text on the television. Every word is written down, so you can understand what's being said. This can be used one-to-one, just following a laptop, or in a group of any size where the text can be relayed on to a large screen. Durham deafened support, have Palantype at all of our large meetings, usually about 6 to 8 a year. If they are dealing with deafness week we have Palantype every day from 9 until 4.

Thank you. Can you, sorry, you mentioned earlier about a Heather Jackson award. Can you give us some details on that please? What the award was for.

Well, I really felt very humbled by this award. I have always been a person who has coped by getting on with it, and I really feel as though I have helped myself by helping others. I have gained much more from the work I do, than anyone could have got from it. But, it was an honour. Especially as I was nominated by Signature, Hearing Concern LINK and NADP and especially as it was the Heather Jackson award. I know for a fact that she would have been delighted for me to receive it. As she had always been so what's the word I am looking for, so supportive and encouraged me all the way along the line, right from the very beginning. At times when I thought well what's the point and I have e-mailed Heather, and had it really bad thought it not worth it I am going round in circles but she has egged me on and she was really, really good.

And the award was for?

The award was for the work I had done in making things better for deafened people.

[01:03:38]

Going back again to family relationships, do you feel that things are very different today, to in the beginning?

Well, in my family, personally thinking things are very, very different. There is much more acceptance about my hearing loss, my husband and I cope very well. There are

still times when I dearly wish I wasn't deaf. My husband especially when he's talking to my son on the phone, 35, 45 minutes and then he will tell me he didn't have much to say. But that is the norm I am sure. I have a very good life. Deafness now doesn't stop me doing anything. The only problem I have with hearing loss is people's attitudes towards it. My grandchildren are very aware of how they need to speak to me, and I think they were more aware from the very beginning. My 5 year old grandson once told a waitress in Asda, you need to wait until my Grandma is looking at you, because she can't hear what you're saying.

Would you say you're opinions have changed over a period of time?

Opinions about, from other people or about myself?

Your opinions towards your attitude yourself about your deafness.

When I first loss my hearing I felt as though I was a nuisance to people, as though I was always having to apologise for being deaf. Apologise for people having to repeat themselves, apologising because I didn't understand what they were saying. Now, although I still sometimes apologise for not hearing them, now I know its not my fault. And conversation is a two way thing. And I will ask people to slow down and speak more clearly, I think in general on a whole things are getting better. But very slowly.

Do you see yourself as a disabled person?

I have other health problems which do disable me but, I feel very fortunate that I can walk to my car, and I can see to drive. But once I get into a meeting, I can be sitting in between a blind man and a man in a wheelchair, and I am the most disabled in that room. My hearing loss has disabled me, I can't understand anything that's being said and without Palantype I might as well not be there.

[01:08:05]

Have you felt discrimination?

Yes often.

Can you elaborate on that?

I feel discriminated against when council, PCT, anyone have meetings and they say we'll have a meeting for deaf and disabled later. I say to them all the time I am a hearing person that's lost my hearing, there's no need for us to be segregated from hearing people, with Palantype we can understand everything that's being said. We want to be in normal meetings hearing what normal people have to say, not just about deaf and disabled, we need to be included. That's my main time I feel disabled, discriminated against.

What about out and about on the street?

I don't think, not too bad. It's not too bad. Sometimes, we had one lip reading group and it was next door to a really very noisy nursery. And they couldn't understand why this room wasn't suitable and they wouldn't change it. We did leave there eventually. I don't think it's much as intentional discrimination, its just more ignorance.

What about if you're in a store shopping, how do you feel dealing with things like that?

Well in one major department store it was Asda actually, 2 or 3 times I asked an attendant where an article was, and I told them I was deaf, but they would walk away and talking as they are going. Telling me where the thing is. And I would just lose them. Later I caught a lady and told her what had happened, and she said 'I will see to it'. But nothing ever did, the next time I went the same happened gain I saw the manager of Asda they came over to Lee House and did some communication skills. I think most people have discrimination, hearing and deafened and once again its ignorance more than anything. I think deafened people have a problem like deaf and some hard-of-hearing when going to the doctors. Not just getting past the reception, but in the doctor's as well. The reception area usually plate class in front of you, and someone looking down, who doesn't, they need to be aware that you need to see their

face. You have to ring them for appointments, or go. There's no text, there's no email for appointments. The last time I was at the doctors I asked the reception would I be able to understand this doctor, because sadly our doctor died, we were having quite a few locums. The receptionist said I quote, 'yes she is lovely you won't have problem'. I went in this was a Chinese doctor. I couldn't understand a word that she said. She may have been lovely, but no disrespect, I couldn't understand her at all. I told her I couldn't understand her she seemed very agitated, 'I said will you please write things down'. She shrugged her shoulders, wrote a prescription down and came out. I came out of the room I went to receptionist I said 'that was disgraceful I have not understood a word she said' and the receptionist said 'I know we have trouble sometimes'. I had to go back and see a different doctor, the next day. This is me who's been deaf for 10 years. And supposedly confident person. What would that have been like for someone at the onset of hearing loss or newly deafened? It shouldn't be happening.

[01:14:08]

Over those 10 years, what changes have you seen? From personal experience, good or bad within the services that the health service provide?

Well, social care and health are much more aware of deafened. When I first went deaf you were either hard-of-hearing, or deaf, culturally deaf, nothing in the middle. PCT health, know about facilities such as Palantype, but because of cost are still very reluctant to use them. I feel things are moving on, but very slowly.

Okay. Can I ask you your thoughts on this project? The oral history project.

I think it's an excellent idea, because hopefully in years to come, people will look back and see great changes. Unlike us. Who look back over the last 10 or 20 years, and see very few.

Are there any particular things that you would like to share with us, any defining moments again, they can be good or bad, over the last 10 years?

I think the worst point over the 10 years is when I was having angioplasty, it's a heart operation a tube goes into your leg up and into your heart. You're awake when this is happening, at various stages you are asked to breath in, breathe out etc. etc.. I was deaf. I couldn't understand what they were saying. At the time, I was new to hearing loss, I didn't have the confidence and very low self-esteem, and I wasn't well. The angioplasty was unsuccessful, this was mainly put down to a bleed, and they said it was because I had not heard what was being said. I had to go for the same operation 6 weeks later, but this time I asked for someone with clear speech who I could understand to stand to the side of me. This worked better. I think that was one of the worst times, it really hit on how deafness could be really a life and death thing. I think some people have said to me, that I went deaf for a purpose. Sometimes I feel this could be true. Because every time I feel as though I have had enough, I really think its time I settled and just with my family and enjoy my family life, something comes along. Someone who is just new to deaf or someone who's not coping, or someone who's had a traumatic experience who brings me back, and think its not over yet.

So, just to coming towards the end now, can you describe as of today, what is a day sorry what is a day in the life of Jane Atkinson like.

Well, I think any day from morning to night, a day, I will get up

A typical day.

I will get up about 7 to 7.30, my husband will have already switched on my computer. I will walk into the small room, check the e-mails and go in, have a shower. After breakfast I am normally in Lee House for 9 o'clock. Any messages or appointments from there. I usually go right up from Consett to Barnard Castle; I can travel anything up to 300 miles a week. That's just round county Durham. I never, never finish a day when I say I have been bored. I really enjoy the work, I get paid for 24 hours but it's usually 54. My family help. Without them I couldn't do what I do. My husband is the home help, when I am not well enough to drive, he's my chauffeur. My daughter takes messages for me at home, she helps out in the office if I am short staffed. And they are all chief cook and bottle washers, we all mix in. I have

excellent volunteers, who help me out both personally and with Durham Deafened Support.

Is there anything that you want to share with us, before we close?

Over the past 10 years I have worked very, very hard in Durham sensitising the needs of deafened people and making deafened people aware of the facilities that are available to them. I think it's very, very important that you have local support for local needs. Which is why we have 7 groups throughout the county. I think there should be organisations like DDS, throughout the county. Throughout the country, sorry. So you have got hands on support, when it's needed. So many people have mental health problems, these problems always recurring. You don't have them and then go away, once you regain yourself esteem. 90% of people get mental health problem back, they have times when they are the lowest ebb, people go from DDS have gone back to college, and back to work. But I see people now, who went back to work 8 years ago, coming back to DDS now for support.

I would just like to thank you Jane for sharing that information with us, and being very, very open and frank.

Thank you.

And for taking the time out to be with us today. Thank you very much.

Thank you.

[End of recording]