



Unheard Voices: interviews with deafened people

Steve Owen
Interviewed by John Hirst

British Library ref. C1345/53

IMPORTANT

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Interview Summary Sheet

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Collection title: Unheard Voices: interviews with deafened people

Interviewee's surname: Owen

Title:

Interviewee's forename: Steve

Sex: Male

Occupation:

Date and place of birth: 1954

Date(s) of recording: 31st May 2009

Location of interview: The Westminster Hotel, Nottingham

Name of interviewer: John Hirst

Speech to Text reporter: Lynn Allen

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Interviewer's comments:

[Track 1]

*John Hirst interviewing Emily Owen's father Steve Owen on 31st May 2009 for the Unseen Voices project at Nottingham with Lynn Allen as the speech to text reporter.
Now, just formally to start with can you just confirm your full name please?*

Yes Stephen Owen.

And your address?

6, Westfield Road Western Park Leicester.

And your date of birth?

16th January 1954.

Can you tell me your family, details of your family please?

Yes I am married to Anthea we have four daughters. Emily who is 30, Sophie who is 28, Kirsty 26 and Polly Anna 22.

And how about grandchildren?

We have no grandchildren. Sophie and Kirsty are married but they have no children yet, so no grandchildren.

[01:13]

Now can you say something please about Emily's history? What happened to her?

Well Emily was as far as we knew quite normal she started off as a normal child and it wasn't until she was 16 that she was diagnosed with neurofibromatosis type 2 or NF2. Which is a genetic disease which affects the nervous system, tumours grow on the nervous system at any part on the nervous system in the body. But always it has bilateral acoustic neuromas which

affect the hearing and balance and they have to be removed surgically because they grow big and they just crush the brain stem other wise. So Emily has had to have several major operations over the past years, and in 2000 she had to have a second acoustic neuroma removed which left her completely deaf. She at that time had an auditory brain stem implant inserted which does give her some sound but it is a little different from a cochlear implant because she has no cochlear or hearing nerve they have been completely destroyed so she has an electronic pad on her brain stem which picks up signals and impulses to help with lipreading. So until she was 16 she was completely as we thought normal, and then she was diagnosed with this illness which we were told would lead eventually to her being profoundly deaf. And that happened as I say 9 years ago now. So, she has had ten or more operations over the past 13 years to remove two acoustic neuromas to remove tumours from her spine, her leg, foot, back, stomach, shoulder. She still has one in the neck that will need removing and some on the back of her leg that will need removing at some time. She has just this year had two more operations to remove growths in her throat they have been removed now and that seems to have gone okay so she is now getting used to hearing with an auditory brain stem implant which is an unusual thing. There is very few people have them. It is very unusual thing to have. So that is her history.

Have any other members of your family had a similar problem?

No, we have once they found out Emily's illness and diagnosed Emily's illness they then did genetic testing on Emily because they know which chromosome the problem lies on, on chromosome 22 so they took Emily's DNA and tested it and found where the gene deletion was they then tested the rest of the family to see whether or not anybody else in the family has it. All her sisters are perfectly clear, there is a possibility I might have a mild form of it or the mosaic form but if I have they are not bothered it is not actually going to do anything so it is only Emily. She is a spontaneous mutation probably. It just happened. So... she is by herself in the family in that sense, yes.

[04:36]

Do you think she was well looked after, do you think you know that the diagnosis and the treatment were as efficient as it could have been or have you got any views on that at all?

Yes we kept taking her to the GP 2 or 3 times because she had bad headaches and could not walk in a straight line we put it down to Emily being clumsy and eventually the GP realised, having thought it was migraines because of exams and things, he obviously decided it was something a little more serious so he got her an appointment at the hospital the next day. And she went and was seen by the consultant and admitted there had and then. She had a brain scan that afternoon and wasn't allowed out of hospital until she had had her first operation a few weeks later. In fact in Nottingham at Queen's Medical Centre her first operation was just down the road from here. Oh so yes, I mean the diagnosis was first class and the treatment from the word go there was first class yes. We were -- we went to Nottingham with her and had consultations with the consultants in Nottingham who performed the operation and no they were, they are very good. Latterly we have been moved to Manchester now we have all her treatment in Manchester because that is the centre of excellence for the illness. She had a team led by Professor Ramsden who do the brain stem implants and remove all the neuromas that she has, so she now goes to Manchester regularly but no the treatment from the medical team has been first class whether in Leicester, Nottingham or Manchester we cannot complain at all they are all very very good, very caring, very helpful. Always on the end of a phone if we want to talk to them we can just ring them up and they will ring back and speak to us if they are not available then so we often speak to doctors on the phone now about treatments and conditions and so on. So no very pleased with the treatment.

[06:46]

What about Emily's education, coming at that stage you say that it started they thought it might be something to do with the stress with exams?

It started really when she was doing her O well GCSEs they are now GCSEs when she was 16. But then she was diagnosed when she was in her first year of her A level course so she missed the end of the first year of her A level course. She did go back after she had had one acoustic neuroma removed so she was deaf in one ear but still hearing in the other. She did go back to college to complete her A levels. Again, the education people were very good they provided a taxi to take her to school every day and bring her home and the college were very good at, you know, making allowances and sorting thing out for her. So she did her A levels and passed her A levels. She was going to go to university to read English, she had been offered a place at Durham. But she couldn't really do that, so she started at De Montfort in Leicester but after

about a term again she had go back into hospital for another operation on the other side and it just became impossible for her to study because of the problems after the operations concentration and memory were being affected by the sot of brain surgery. So, really she had to stop her education at that point. So she got her GCSEs and A level was going to read English at university but that I'm afraid did not work. Not because of the university's fault they did support her all they could but she just was not physically able to do the work. So, she just lives at home now she cannot work I mean she does not have the strength to be able to do things on a day-by-day basis. I mean she has some good days and some bad days and sometimes she is too tired to do very much other days she is not too bad it is very variable. So she lives at home with us now.

Does she have to have some regular check ups, or do you rather wait for something so to speak to crop up before you have to approach somebody?

She does have regular check ups at Manchester they tend to scan her every one or two years depending on what they have seen on the previous scan so we go to Manchester every year. Well we are in Manchester every year to see the consultants and every year or two they will give her a scan to see whether there are any more tumours growing or what state the tumours are in. But we can always ring at any time if we have any concerns we just ring, we have a direct line through to the secretaries now we just ring and say we would like the see the consultant and they will arrange an appointment normally within the next couple of weeks so we just go up to Manchester then to see them. So, we are in Manchester six or seven times a year probably. Because with her brain stem implant as well that needs to be checked and tuned at the university in Manchester, so we go up fairly regularly, yes.

[10:04]

How active a life can she lead can she do any hobbies or can she go for walks or anything like that?

She used to be able to walk reasonably well until she had a spinal tumour removed a year ago in May 2008. That left her paralyzed initially from the waist downwards. And gradually over the year with physiotherapy and so on she can now walk with a stick. Yes, a reasonable distance but it obviously severely limits her mobility so she does have a wheelchair we take

her around with us she cannot go out by herself very far at all, no. But if she is with us we can take her in her wheelchair and take her stick with her so she can get out when we get to a places and do a little bit of walking. But really it is very difficult for her to go out by herself. She couldn't go very far at all. She wouldn't be able to go into town or anything like that, no. No.

It must affect her social life. How is she getting on in that way, meeting friends?

It is difficult she has got one friend who remained with her since school who is very good and lives not far away and arranges to see her quite regularly. She has a lot of friends at church, who do quite a lot with her, invite her out come round and fix her up and so on. But yes it is not easy because a lot of her friends are now getting married and having children and the problem with Emily's illness is, if she does have children there is a 50 per cent chance that they will be affected by the NF2 that Emily has so she has made a decision she is not going to get married not going to have children. We will have to see I guess, but you know it is quite a thought that if you do have a child there is a 50 per cent chance it will have the same illness that Emily has, which will lead eventually to deafness and other problems. So, it is a bit difficult for her, she sees her friends growing up having children and I think she was saying she has been a bridesmaid about 6 times and God mother to I think 5 children now. So, you know. But she can't well she won't have her own children anyway. Unless they come up with some treatment I guess, but you know she is 30 now so there is always talk they will find a cure for this disease, but you know it is a little way away yet.

[12:39]

It has obviously had the most dramatic effect it could possibly have on her life. How do you feel it has affected the rest of your family?

Yes, well it obviously had a big effect on the whole family. I think on Sophie who is the sort of second one down Emily is the eldest daughter then it is Sophie she feels in some ways she is the oldest now and has to take that responsibility, because Emily cannot do a lot of things that you know you expect your older sister to be able to do. So I think it affected Sophie quite badly at the time, that this was her older sister but you know she was now deaf and couldn't do a lot of things and Sophie had to sort of fill in that role. The other two Pollyanna was a little

young the youngest was a little young when it was all happening so I think it is affecting her more now than it did at the time. Because, you know, at the time she was at junior school and things just carried on really, you know. I mean I think she is more affected by it now. She is actually at university at the minute in fact she is travelling home today from St Andrews she is up at St Andrews studying. So, she finds it a bit difficult sometimes I think to see her oldest sister not being able to do the things that she can do. As far as my wife and myself are concerned, obviously it has been a major change my wife had to give up work to care for Emily. And I guess at this stage in life we would have expected to be just the two of us now with our youngest being 22 just with the two of us and we could be a little freer shall we say to do different things. But it has not worked out of course, because Emily is living with us now, so although the other three have left home we still have the eldest you know living with us which is a little strange isn't it you know. So I think they find that a bit difficult. So yes it has had a big effect on my wife and myself obviously, yes.

I didn't ask what job you do yourself?

I am a teacher I am a mathematics teacher.

So you are fairly settled in one place you don't have to move about?

No that is right. I mean, we live in Leicester we have lived in Leicester for years and I guess I'll be staying at the same school until I retire now because I have only a few years to go to retirement so no we don't move around, and we have stayed in the same place I mean we are thinking of perhaps it is time to begin looking for somewhere to move to, with Emily in mind as her mobility is getting worse and obviously she has no hearing now and perhaps a bungalow or something like that might be more appropriate. As we live in a house at the minute.

Have you had to adapt the house in any way?

Yes, I mean we have had to have handrails put in at the doors so she can get into the house we have got hand rails up the stairs. We have had to have the toilets, the supports around the toilet. We have put a separate shower room in, things like that. Not major in the sense she can still get upstairs with the handrails so we have not needed a stair lift yet. Or anything like that.

But yes, I guess they are fairly minor things but yes we have put grab rails in on the stairs handrails and so on, so yes minor adaptations. Which have been sorted by social services they have been very good at that side of things. You know, we have just told them what we needed they have come round and assessed it they have put grab rails in the showers on the stairs and handrails and so on. So yes they have been very good very efficient at that getting it done.

[16:37]

What about holidays have you been able to go away on holidays?

Yes we do go on holiday. Obviously we take Emily with us when we go. I mean as I say, mobility wise she is a lot worse now than she was last year, 12 months ago as I think I said she had a spinal tumour or two spinal tumours removed which have caused some damage to the spinal cord but no we do get on holidays I mean two years ago we went to South Africa. Kirsty our third daughter lives in South Africa she married a South African and is living near Johannesburg so we went out with Emily and spent a few weeks in South Africa which was great, you know we managed that okay. Last year we didn't get away because Emily had had this operation and was basically in hospital for about 3 months, May June, most of July so then it was regular physio up at the hospital a couple of times a week so we didn't get away very much last year. We are hoping this summer to go to the States, because Sophie our second daughter is living in the States at the minute. So the plan is to take Emily with us to the States and see how that goes. It will be a little different because as I say her mobility is a lot worse than it was she could walk reasonably well two years ago, whereas now she can't walk without a stick and she can't walk very far anyway. So we will give it a go see how it goes.

Do you ever find when you go like that that there is not enough effort made by the public or by people on transport helping or do you usually find that you get reasonable help?

As long as you are out of Britain you get good help. The countries we have been to which are a few with her over the last 13 years we have been to Spain, Majorca, Tenerife, South Africa, various places. As long as you get out of Britain you are fine. I am afraid that is the way it is. Or appears to us. In Britain they don't care. They will tell you that you get support and help and so on, but it never materialises. The railways are useless we find, we have had Emily go up to visit her auntie up in Newcastle and we have had support for her and you know they have

known she is deaf and so on, and then one journey the train stopped for some reason, just past York somewhere a station past York and everybody was told to get off well she didn't hear the announcement of course they just left her on the train fortunately the last person getting off said "you have got to get off here". Well "why I don't know they have told us all to get off", "well what do we do". Well I don't know. So they stand on the platform and of course an announcement comes over the tannoy go to platform so and so pick up a train of course fortunately this gentleman realised Emily's difficulty and said to her well they are telling us to do this, but British Rail were absolutely useless. I am afraid it seems to be every journey she is not so keen to travel by train now because of these problems. They promise you all of this, and we complain every time and they just write a letter back saying very sorry it won't happen again and here is a £ 5 voucher for your next journey and that's all they do. You go to the airport they promise you support for her when she gets off the plane, but it is never there. So either you get on without it or you kick up a stink. At the end of the day after a flight you can't be that bothered so you just sort yourself out I am afraid. Whereas you go to other countries Europe, even South Africa, people are there they have special check in desks for the disabled, they will take you through in the wheelchair, they will push you through, leave you at a place in the departure lounge say we will come and get you when it is time for the flight and they do. I say "I will push", "no it is all right" said "we will do the wheelchair you just follow us" and yet you know east Midlands airport we have had problems there you know they don't do anything there you end up sorting yourself out, Heathrow is the same. Edinburgh we have been to, as I say in Britain they don't seem to care they will tell you they do they will say they have got all these systems in place but that you never work. But as soon as you get abroad it is just a completely different culture except for France actually I have to say France is bad. But yes it is a different culture they are more equipped they seem to be more ready for it, and more willing to help. As I say Paris is bad though the Metro in Paris that is not something to attempt with either a wheelchair or even a child's buggy they are totally disabled unfriendly in the Metro in Paris we have tried that. But we found when we were abroad with Emily actually object holiday people are very supportive and very helpful and, you know, they will except again if Britain. It is strange we go away with Emily in the wheelchair in Britain nobody seems to care you are trying to push a wheelchair around and people will not get out the way they just stand in the way. There is not many drop pavements in Britain you know you find you cannot get round places in Britain the same whereas you go abroad and I don't know it just seems so much easier and more disabled-friendly. It is strange I don't know why. As I say when we went to South Africa there was supposed to be support at Heathrow airport but we

never saw anybody. Never saw anybody. You get to South Africa the bloke is there “yes we will take you through” he asked me if I wanted to go through, or whether he should take her and took her all the way to the little area where the plane was going to depart from you know pushed her all the way there saying this is where you will be, pointed out the screen to her told her what would come on the screen made sure she understood and sort of said “okay I will leave you here now but I will come back when the plane is due to board” and he did. But as I say Heathrow they don't care. But you just have to accept it and get on with it don't you?

[23:16]

If she gets in a case like she did when she was on the train virtually abandoned in that sort of case is she ever prepared to speak out and say I am deaf can I please have some help?

Yes she will she will now she found it very difficult initially but she will now she does tell people but the problem is that if you don't know there is a problem then the train stopped in a station as far as Emily is concerned well it has just stopped in the station you know. She is reading a book and you probably don't notice you have been there 5 minutes rather than 2 do you then she happens to look up and sees people getting off the train, well that what people do at a station isn't it you know. But no she will say. Well of course we had the guard knew that she was deaf, I mean it had all been explained to him we had had somebody at Leicester station getting on the train and so on. But by the time it got up to York they just forgotten all of this, or whatever and they just got off and left her. You know. But no she will tell people that she is deaf.

Has anybody ever been unpleasant to her in a way that sort of bullying or laughing at her or make her feel really embarrassed.

No I don't think so, no. I don't think she has ever had that. No. No she hasn't. But obviously until recently without having to have the stick, I mean it is not that obvious there is a problem. You know, with the deafness I suppose that was her only problem in that sense. And if you look at somebody you don't know they are deaf do you.

That is right.

But no she has got a stick and so on perhaps it is a bit more obvious but no she has never really had any bullying or anything like that, no. No.

[25:10]

Lipreading classes or anything that would help with her deafness, does she join in that at all?

Of course, we were in the strange position we knew she was going to be deafened, you know, this is the thing about Emily's illness you know you are going to end up deaf at some point. So once she had been diagnosed and had her first operation which left her Deaf on one side we then enrolled for lip reading classes. Sorry sign language classes BSL class it is whole family all six of us we used the go tonight school to learn British sign language ready for when Emily was deaf. So, we all have a rudimentary knowledge of British sign language shall we say apart from my wife who is very good at it, well I say very good both Emily and her have level 2 British sign language so they can communicate very well with sign language. Lipreading classes yes, we were given lipreading classes in Nottingham at the city hospital in Nottingham that was organised by the people at the Queens Medical Centre again for the whole family. We had a series of lipreading classes that they put on for us. Emily is very good at lipreading, but I don't think it is something you can learn really. They were telling us either you tend to be quite good or you tend to be not so good and I couldn't really get the hang of it to be honest. But Emily is good at lipreading. She is very good. And with the implant it does help because it gives the rhythm, she picks up impulses so it give it is rhythm of the speech and coupling that with the lipreading she can get well on the tests that she does every year, because she has a test every year on how the implant is working with the lipreading and the implant working together she gets well over 90 per cent accuracy. With lipreading alone I think it is around 60 per cent. So, but yes I mean we were given those. I mean as I say we can't complain with the NHS at all they were very good as I say we were given these lipreading classes and sign language classes.

So Emily and my wife carried on sign language classes for quite a long time. We just did stage 1 the rest of the family we got stage 1 BSL and called it a day.

Would you prefer her to rely on sign language when it was available, or would you prefer her to lipread and try and hear as much as she could?

I think lipreading is preferable if it is possible, because BSL is a bit limiting there are very few people who speak it, well I say speak it or use it. So you need somebody who knows and understands it. It is useful on occasions between my wife and my daughter that they can communicate using the sign language fairly quickly and efficiently but I this I in a general situation so few people use it that if we got to rely on my wife to listen to what is being said, then translate it to Emily, it does make conversations very stilted. Whereas if Emily can just lip read as you are going along obviously it does make the conversation flow a little better and she feels, you know, more involved in it I think but if it is a case of somebody has to say something, we all stop, my wife or myself sign it to Emily, then we carry on you know, it is very stilted because it is not as if everybody in the group is going to be speaking sign language. We are never really in a situation where we could just hold a conversation in sign language because there are always people there will who do not understand it at all so you are having to speak anyway and trying to use the two languages it does get a little bit confusing shall we say.

[29:27]

If you have got a number of people in the room say having a meal with some strangers does she cope all right there?

It is difficult. If there are people we don't know it is difficult because they do not tend to understand the etiquette of having a conversation with a deaf person. Making sure they are looking at you and so on, and making sure it is clear who is speaking so that that is difficult for her. Meal times are difficult anyway because you have got to eat if you are eating you cannot be looking at who is speaking can you. So meal times are not a great time for Emily to be having conversations really no she tends to just sit and eat.

Do you find sometimes that you have to be the intermediary if you know what I mean? Explain to her what somebody else is saying or?

Yes, yes I mean there are some people she finds difficult to lip read so yes there are times when we are having to interpret what they have said to make sure Emily has understood. One of the biggest problems we find is sometimes she thinks she has understood but she has not actually. You know she thinks she knows what they have said and it makes perfect sense to

her, but it is not actually connected to what they have actually said. So that is a little bit of a problem sometimes we ask her have you understood that Emily she will say yes, and then sometimes we are thinking well could you just tell us what they have said then Emily just to make sure that she has and sometimes we find it is completely different from what they have actually said. So yes, I mean if none or neither of us are around it is quite difficult for her sometimes. Unless with people who know her well, then it is not a problem because they know what to do, they know how to speak to her, they know where to sit and all those sorts of things. And obviously they understand that she has these understanding difficulties and they do make sure she has understood. But with fresh people it is very difficult. Particularly in a group because you don't even know who is speaking to you never mind what they are saying and there is three conversations going on at once so it can be difficult, yes. It can be it can be quite isolating I think.

[31:56]

This is an awkward question but what do you think about the future?

Well it is difficult, I mean we have to be honest and say it is difficult. I mean Emily is never going to be able to look after herself on a long-term basis. I mean, the nature of her illness means she is going to get worse rather than better. There will be more operations in the future and any operation however minor in that sense is going to cause damage because all her tumours, they are benign tumours it is not as if they are cancerous, but they are always growing on nerves so when you remove one you are removing a nerve at least or several nerves and obviously some nerves are more major than others. So yes the future is difficult I mean obviously we have to be pragmatic I suppose and say well my wife and myself are getting older, sorry, her sisters have said they will all look after her when the time comes she has 3 sisters and they have said they will so have the two husbands of the married ones and I get guess you have just got to leave it there haven't you. I guess you have got to say well you do what you can while you can and when you can no longer do it then hopefully there are other people who will. And that is it. I mean you get very little support from you know sort of social services or anything like that. They are not particularly interested. But you know you just get on with it I think. I guess you just have to get on with it and that is how it is and there is no point sitting around moping about it that is the life and you just get on with it. And there will come a time I guess when we cannot look after her she needs to be looked after and

we will have to pass her on to her sisters I suppose. But yes.

You are obviously very supportive family, which is wonderful for her. And you did say she gets friendship and support from church people?

Uh huh.

Now, have you as a family got a Christian faith?

Yes, yes. Yes we have a very strong faith and Emily has a very strong faith and that has helped her through this certainly. We attend a Baptist church in Leicester. And I think Emily's faith has got her through a lot of what she has gone through because we see some of her friends with a similar illness well with the same illness you know, and to them life is just a drudge really you know. And our view is well that is this is life you get on with it, you live it as you can. Do the best you can as you can and okay Emily is not doing what she would have chosen to do, but she gets on and does what she can. That is all we can do. But yes the faith certainly has helped her through this I think without faith it would have been very difficult to have your daughter diagnosed with this illness, to be deafened to be paralyzed after an operation okay she is getting -- that has got a little better over the past 12 months but it is not going to get any better now I think she is as good now ability wise as she will be. And I think without faith it would be very difficult to make sense of it really. If one ever can make sense of these things. Yes so...

[35:22]

Do you think she was happy to come here, it is quite an event for somebody isn't it?

Oh no very happy, her view is anything she can do to help has got to be positive so she is always doing any research projects at the university in Manchester, or if they want people to speak to newly diagnosed people who have got Emily's illness she is happy to talk to them. She spends quite a lot of time e-mailing people who have got the same illness and chatting to them. No, she sees it, as her opportunity to help where she can so if there is the anything happening at all that helps in any way, then she is quite happy to be part of it and wants to be involved. You know what she can if it is going to help anybody else that has always been her

attitude. But it is the same at the hospital when she is in hospital she is always going around chatting to other patients that is Emily you know, just help who you can while you can. You know what I mean it may be of benefit to somebody at some time. So no once the letter came through she showed it to me and said "I want to go you know we must go to this you know". So, we have and here we are. So no she will find it very helpful I am sure she will find it helpful to herself to be able to just talk to somebody who is not family if you like, about what has gone on, you know. She has always found it useful to have somebody outside of the family, you know, to just talk things through. I mean the early days again the NHS were very good they put her in touch with a psychiatrist who herself had been deafened during training and she used to visit her on a regular basis in Leicester and then eventually the consultant came round to our house to visit Emily and talk to Emily about issues of deafness which she herself knew because she had been deafened while she was training to be a medical student you know she was a medical student and yes Emily will find today helpful because she can talk to somebody she does not know, just say things how it is and move on.

Other methods of communication does she use the Internet and that kind of thing the talking her friends communicate with her friends?

Yes she does is it face book it is called face book isn't it and all these chat things with her sisters they have a chat room with her sisters as I say they are round the different parts of the world at the minute so yes Sophie is in America Kirsty is in South Africa and Polly Anna was in Scotland until today she is heading down back do Leicester today and they do set up regular chat room things where they sit and type to each other. And yes, she contacts by e-mail and text she has a phone mobile phone about the text is really great. I mean in some ways I think if you were going to be deafened this is the time have been deafened with all the aids to communication that there are. You know with text phones and Internet and you know. But no she uses that a lot, yes.

So she never really feels cut off?

No, I mean no, she can communicate I mean obviously more cut off than she would have expected to have been and only more cut off than we would be but no she does have communication with people and you know not completely cut off, yes, yes.

[39:10]

Is there anything else you would like to sort of say about this. I think we have covered quite a wide range?

I think it is just again I think one of the issues is knowing what support is available. I think that was something that in the early days was difficult for us, knowing quite what support is around. Who can support you, who can provide what. I mean we had a lot of run-ins with social services for instance finding it difficult to access the stuff that she needed initially unless it was through the health the people in the Health Service were brilliant but when she went on to try to sort benefits and things out and allowances and things I mean that is an absolute nightmare, an absolute nightmare they steam to set up systems just to catch you out. We had a lot of trouble with them in the early days it has to be said. And I like to think I am a reasonably intelligent person, but I couldn't fathom out some of the things they were on about. I mean I really couldn't it did not make sense and I had several meetings with them explaining why these things didn't make any sense at all and asked them questions that they couldn't answer them, and you know you get very frustrated trying to access these things. And I know these people are busy I am sure they are busy, but in a sense that is their job isn't it?, and they were quite unhelpful it has to be said. I mean, I had to sort of threaten my MP in the end before anything actually happened. I sort of gave them a deadline of a fortnight otherwise I was contacting my MP. Strangely a fortnight after exactly all the information dropped through on my door it had all been sorted. So I think it is things like that that people perhaps need to know, that you are not going to find it easy but you do need to just stick at it and don't give up. I think you know, but our life is different you know life has changed completely for us from what it was and what we would have expected it to have been I think. But life is still life and Emily is still Emily and we still do lots of things together you know. Going to lots of places and Warwick Castle last week and Abbey Park in Leicester yesterday, and we are here today and just enjoy life while you can because nobody knows what is around the corner do they? So just do what you can while you can that our motto and enjoy it. Yes.

Well I think that covers everything I would like to ask. You have been very, very frank. It is most interesting and I think that in a way somehow Emily and your family seem to be coping in the most remarkable way. I am very grateful to you for coming in today?

It is a pleasure.

And very grateful to you also Lynn with hell witness doing the text because all this now will go on to a tape. And you will see a transcript?

Right uh huh.

[42:42]

Is there anything else you would like say before I press the stop button?

I cannot think of anything. Well, I guess one thing we found as well is there is a slight difference between the deaf community and the deafened community. When Emily was first deafened we used to go along to the centre for the deaf in Leicester, and they run various things and we would try to get involved but we found it didn't really work. That if you are born deaf it is completely different culture, way of life from somebody who is deafened at some point during their life. And there does not seem to be that sort of interlinking of those two communities they just seem pretty different somehow. I think if you are born deaf then your whole culture is based around that isn't it and everything you do is based around that whereas if you are deafened later on in life you have still got memories of hearing, memories of living in a society where you could hear and that certainly influences you quite a lot. So we have found that actually trying to mix with the deaf community does not work. I mean they are very nice don't get me wrong it is not as if we are ostracised or anything but you just found that you could not really understand them in that sense, you could not really understand where they have been coming from and what their issues were and you know, we found latterly that we just don't really, I mean we now I guess the people who are deaf that we have contact with are those that have been deafened, particularly obviously with the same illness that Emily has. Although there are not many of them about, but you know we do try to spend time with people like that and we have people come over and stay with us and Emily goes and stays with them or has done in the past. She has not been for a while now. So I think that is something that took us a while to adjust to. We assumed once Emily was deaf then she could become part of the deaf community, but it does not really work. It is like three communities the hearing community, the deaf community and the deafened community. And I think you are very much part of one, you cannot really straddle it I don't think. I just found it quite interesting.

Although again when Emily was first diagnosed she was given a social worker from the Centre for the Deaf in Leicester, who did help with some issues you know to do with her communication, she sorted out doorbell for us, and alarm system in the house for Emily so you know so she has a pager thing. So it is connected up to a fire alarm and the doorbell and she has the shake awake alarm clock. And there a sort of pager button we can press if we are downstairs, you know we have one we can press and it just lets Emily know that we want to her to come down or something it just vibrates on her little pager and the light comes on as to which alarm is going off. They sorted all that out for us at the centres for the deaf they have done all that. So certainly we found those agencies very good the NHS the NF the association, the Centre for the Deaf it is just when you start dealing with the big social service network that it just all falls apart. I mean, I don't know whatever reason it is difficult to say isn't it. You know but our experience is not unique shall we say from what we have heard talking the other people. But no, overall I mean we have been supported. But once you say to the people like social services that Emily is living with us and we are happy for that then they are not interested. You know, they pay my wife I don't know is it £35 a week or something for looking after Emily and that is it full stop, end. Whereas obviously if she was not living with us then we would be sorting out housing benefit all sorts of things for her. But they are not interested once you say you will have her at home with you that is it. They even took, we did for a while get some council tax relief, we were down a band because we had to do all these alterations to the house. But they came round last year and said no they are not major enough we will take that off you now you have got to pay your full council tax and you know, that is just you know we found the big organisations are not particularly helpful. But the smaller ones are, I think you have got to accept that is life and get on with it have an you. I mean there is no point ranting and raving to these people they are only doing their job as they see it I suppose. And you know, that is it. Life goes on.

Shall we bring it to a close?

Yes okay.

Thank you very much again?

Thank you.

[End of recording]