

## ORAL HISTORY RECORDING TRANSCRIPT

### 'Fighting for our Rights' project

<b>Surname</b>	Carpenter
<b>Given names</b>	Jennifer Daphne
<b>Date of birth</b>	1950
<b>Place of birth</b>	Belfast, Northern Ireland
<b>Date of interview</b>	14 June 2017
<b>Length of interview</b>	00:58:12
<b>Number of tracks</b>	1
<b>Name of interviewer</b>	Jen Kavanagh
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Q: This is an oral history interview with Jennifer Carpenter by Jen Kavanagh on Wednesday the 14 June 2017. The interview is taking place at Jennifer's home in New Malden as part of Kingston Centre for Independent Living's Fighting For Our Rights project. So thank you very much, Jennifer, for being interviewed for this project, could we start with you stating your full name please.

A: I'm Jennifer Daphne Carpenter.

Q: And what is your date of birth?

A: [REMOVED] 1950.

Q: And whereabouts were you born?

A: I was born in Belfast, Northern Ireland.

Q: And when was it that you moved over to the UK--, to England?

A: I came here in February 1973.

Q: Okay. What, erm, what were your parents' names?

A: My mother, Christina and my father, James.

Q: And what were their professions?

A: My father was a civil servant and my mother was a full time mum and housewife.

Q: And why was it that you moved over to England?

A: I came here for love.

Q: Oh, okay.

A: I met a chap in Belfast--, well, outside Belfast, who worked for the BBC and we went out together for a year and then I came over here.

Q: Excellent. Whereabouts did you go to school?

A: I went to school--, well I--, we moved from Belfast down the Ards peninsula, which is quite beautiful and quite remote, so I went to the local village school. I lived in a little place called Millisle--, M-i-l-l-i-s-l-e, which is beautiful, and then I did my secondary education in Donaghadee and then my father was promoted and we moved to Belfast and I went to college in Belfast itself.

Q: And what was your educational experience like?

A: Fine, I wish in a way that I'd gone to university, I didn't, I should have [laughs]. But I was educated up to A Level, I didn't go any further.

Q: What was it that you did when you finished school?

A: Sorry?

Q: What did you do when you finished school?

A: Erm, what did I do when I finished school? I went into--, I was working for a legal company, so my background really has been legal. And then I came over to London and I worked for a computer company, but I went into human resources, I like to call them human remains. So I was doing lots of graduate recruitment, different stuff like that.

Q: So at the point when you lost your sight where were you in terms of your career, where were you working at the time?

A: I was at home with a baby who was three and a half. I lost two children before Nick and I was very keen to be a mother, and I lost my vision over three weeks. And I was just sorting his--, I think he was just four--, just coming four, I was doing his birthday party and, you know, within three weeks I was registered blind.

Q: Can you talk me through sort of what--, what caused that, what the--,

A: I've got a very rare genetic disorder called pseudoxanthoma elasticum, PXE for short, which is systemic, it's chronic, it's degenerative and it's a connective tissue disorder. It affects your--, everything, every organ in your body, I have hyperextensive joints, I have skin lesions, I've been haemorrhaging into my eyes, that's why I've lost the sight, I've had a couple of bleeds in my brain, I have hyperextensive joints, I have heart problems and I have vascular problems. Apart from that I'm pretty fit.

Q: Had you had any symptoms regarding your sight prior to the sight loss?

A: Nope.

Q: Okay. So it must've been quite a shock?

A: Yes it was, a massive life change, mmm.

Q: And in terms of that deterioration, was that--, so was it quite gradual over those three weeks or did it--,

A: No, it was--, I didn't know what was going on at all. The world started to become a very funny place, it started off with watching the television and the screen wavering, went out into the hallway, loads of photographs out there and I was taking my child to playgroup and everything was all wavering and when I got out onto the street people were--, had massive big long legs, small bodies and everything was leaning over to the right. What I didn't know at the time was I was having a massive eye haemorrhage and it was tipping my retina so everything was hanging over to the right. And I tried to get some help from Kingston Eye Hospital, in fact I went to the doctor and they gave me an appointment--, this was May, they gave me an appointment for December, and a friend of mine said get to Moorfields which I did and they said right away you're having the mother of all eye haemorrhages. They actually had 50 people with my genetic disorder, so they'd seen it before and they lasered me but we know with hindsight you shouldn't be lasered because you can't see through a scar. So they created a scar in my right eye but the thing continued to bleed. And with PXE, what happens on one side of your body happens on the other within two years, but unfortunately within three weeks I was just, you know, bleeding so much that it just wiped the vision away.

Q: And have you had any treatment to--, is there anything they can do in terms of trying to restore any--,

A: No, there's nothing--, there's nothing they can do. But ten years ago--, they can now inject people who have got age related macular, which is not what I've got, to seal the blood vessels and stop it, but too late for me.

Q: Okay.

A: You know, but by which time, I mean I'm talking about '91 now, so it was--, I'd had it by then.

Q: So what--, what sort of support were you offered in those early days when--,

A: I was offered nothing to begin with, I contacted social services--, my husband did, to be told there was a nine month waiting list to see anybody from sensory impairment and my husband said we're at home with a child approaching four, my wife was driving the car three weeks ago, she can't even leave the house, get your act and get round here. And I think within two days I had five social workers in my house because he went to the--, Roy Taylor who was the Director of social services then, who's a brilliant bloke and he was very into disabled people and, you know, helping out, and Jenny--, Jenny Webb, she was the Deputy Director, two wonderful, wonderful people. Because they were into KCIL, they were into disability and getting things worked out. So what did I have, I had somebody who came round and stuck blobs on my washing machine and my cooker, and then they got a mobility officer to come round and try and help you get out and about, but I had the problem of a young child and it was just like you woke up into the middle of a nightmare because life just, you know, changed over three weeks. It's--, it just--, that was it, that was the end of my--, a normal life if you like.

Q: When were you first made aware of the independent living scheme?

A: Er, I think round about '92, because what social services did was, they provided me with a lovely girl called Louise and she came, I think, a couple of hours a day. Because I couldn't walk my child round to playgroup or anything, and he started school that year and I couldn't do anything. I didn't know how to cook--, I didn't know how to function, because if you're sighted and then this happens to you, it was like being beamed onto Mars I would say [laughs], without a map. So I think it was probably about '92 that I got in touch with the independent living scheme.

Q: And how did that work, how did being in receipt of those payments work for you?

A: Er, it was mixed really, er, I don't think KCIL at the time understood the needs of people with a sight loss, because you can't fill in forms, you can't read anything they're going to send to you about people's CVs, I had a problem with that. I explained the situation but you get a bunch of stuff that would come into your house and you couldn't read any of it, you couldn't access it. And also, over the years going to the KCIL AGMs and stuff, there was nothing made available really for people with a visual impairment. I've struggled with that, I've struggled at the AGMs and everything else with not telling you who's in the room. And I think from my perspective, and a lot of other blind people, it was very much geared at that time for wheelchair users and it didn't really address the other disabilities.

Q: Yeah, absolutely. So once--, once you were in receipt of the direct payments, what was it that that was helping support in terms of your--,

A: Well I had a--, I recruited a PA called Carol who's a Scottish lady, and she was with me--, I was assessed by social services and I got eight hours a week. And she would help me, we'd go down to the supermarket together and do the shopping. She would help me--, she would read my paperwork, she would help me sort of clean my home and just do stuff. And because Nick was so tiny she also--, I got her, I think, when I got her--, that sounds good, when Nick was five so I would go out with her in the school holidays, we'd go up to London, we'd take the children because I couldn't take my child out on my own. So that was great that her little boy was the same age so that sort of helped a lot. Er, yes, just trying to shop, trying to cook, trying to read cookery books, trying to--, well she had to read me all the recipes. Things have moved on on the technology front for blind people now, so I've got all sorts of gizmos at home [laughs].

Q: [Laughs]. In terms of you having such a young child at that time, was--, was there supervision put in place or was that taken into account in terms of the services you could offer--, access, sorry.

A: No, nobody took into account the fact I had a young child.

Q: Yeah.

A: And my--, I have no family over here, because I'm from Northern Ireland. You rely on, I suppose, people you meet, other mothers, but it's very hard to meet people because the world is all about body language and eye contact. And I couldn't walk to school, I had to--, I walked with four or five other women, I used to meet them at the corner with Nick and I would walk back and forth with them, but I never met anyone at school outside those five people. Because people might be smiling and looking, if you're not doing that it's very, very hard, being visually impaired. So none of that kicked in at all, and I feel quite sad about that really.

Q: So when you sort of receive your assessments then, in terms of receiving direct payments, that didn't include anything regarding sort of childcare or support?

A: No.

Q: Okay.

A: And when--, on reflection, eight hours a week is nothing, I know a couple of other people who were blind then had children and they've--, as things have moved on, maybe ten years ago, they've been awarded something like 28 hours a week. Where eight hours is really nothing. It's better than nothing but it's not a lot.

Q: Yeah. Yeah, absolutely. How do you feel that the support you received sort of in those--, very much sort of at the beginning in those early days has changed to what you receive now?

A: I don't receive anything.

Q: Oh, okay.

A: I, erm, I pay privately for any help I want. I used to be--, do the garden, I can't do that, I couldn't do that since '91. I pay for a gardener, I've got a lady who comes in on a Thursday, three hours a week to do my admin with me, my husband, who's now retired, does the shopping. I do most of the housework, he hoovers, I'm the duster and scrubber but I need some help, but it's very hard getting anybody. I did have someone coming in to do the bathroom and the kitchen and run the Hoover around, but I could only stick her for six months because of her attitude towards me. Constantly telling me I look perfectly fine, she couldn't believe that there was anything wrong with my eyesight, and this has gone on right through my visually impaired life. It's a real hassle, but you know, you get it in shops, you get it everywhere. I do know what they think, people who can't see very well, what they look like and I get all the same thing, you don't look blind. What am I meant to look like? [Laughs]. Should I have a flashing sign above my head? [Laughs].

Q: [Laughs]. Yeah, absolutely.

A: I don't know.

Q: So in terms of sort of your--, I suppose your involvement within the blind and disability community, when did you first get involved with the access committee at KCIL?

A: Probably about '92, '93, because I got involved with social services half way through '91 and then the sensory impairment team were down at the Crescent Resource Centre--, which was shut, incidentally, in August 2011 to enable all of us disabled people to be part of the community, which really means you're stuck indoors on your own. Er, so I started, I think, first of all on the access committee 'cause I knew a couple of girls--, I'd met a couple of other mums who were physically disabled, so I started doing KCIL then. I was on the holiday committee and I was on another committee, it's sort of lost in the mists of time really. I did all sorts of stuff like that, but I got involved with the Kingston Association for the Blind as well, I was their vice chair at one point and I started a buddy scheme in 2000 and I've got involved with the tandem scheme, setting that up, and also some of the blind clubs. And my problem was I was in my late 30s and I didn't know anybody who was visually impaired, I'd never met a blind person. I think I tried to get a guy across the road years ago with a guide dog, and how stupid is that? But anyway, I tried that. I'd never met anyone who was physically disabled, when you're in the world of you're driving your car, you're working, you're having children, you just don't come across people with a disability. But when it happens to you of course you do 'cause you then link in and I know loads of people with disabilities now, and what a lovely lot they are [laughs], so different from, erm, you know, other people really.

Q: Did you feel sort of quite--, did you want to be quite proactive in terms of getting involved with the community?

A: I'm the sort of person--, I'm a very--, I'm Northern Irish, we're very friendly, we're very outreaching, we're very helpful, and I like to chat and you engage with people all the time, well I do--, I try to anyway. If I go somewhere I would talk to people, and it just came--, it was just a natural thing for me to do. It was wonderful to go down to the Crescent and meet other people who were visually impaired. But the thing was, these people were all in their 70s and 80s or 90s and I was standing alone with a toddler and there was no contact with other visually impaired mums. But what I did do in the Crescent, I got involved with a disabled parents group and that sort of kicked things off as well, you know, getting into that world and, er, I suppose I wanted to encourage support and make things better for other women who were--, and men who were losing their sight.

Q: What did the disabled--, sorry, the blind parents group involve?

A: It wasn't a blind parents group, it was a disabled parents group--,

Q: Sorry. It was a disabled, sorry, yeah.

A: And it was down at the Crescent and it was mostly wheelchair users. Er, I'm trying to think, were there any other visually impaired people? Probably one other, but it was mostly physical disability. Er, what did we do? Well we talked about different issues and we made representation to schools, I've talked at that eye hospital about what it was like to lose your sight suddenly and have a young kid, just like that, and trying to move things on and, yeah, make representation really.

Q: And was it at the Crescent when you were learning braille?

A: I did braille because I thought I was going to go mad, but then you can't sit and read a braille thing when you've got children running round your house. I did it as an intellectual exercise. It didn't work because the guy that was teaching me was quite elderly and they were ancient books. What I did, I did a thing called Fingerprint, which I did at home with--, it was an audio system and I just really taught myself. But it was nice to go down to the Crescent, meet people, all the social workers were there, there was the canteen, the spirit and the love in that place was tremendous, it was full of laughter, you know? And I'm in a world where all my able bodied, wealthy and healthy friends are moaning about I've chipped a nail, and you go into the Crescent where people are really struggling with life and they're all laughing and supporting each other and having a nice time.

Q: What other services did you access when you were there?

A: Nothing really, I mean I suppose I just, you know, chatted to people--, I did a volunteer job down there as well, I helped out in their equipment shop [laughs], that was good fun, with the OTs. Er, just braille really, you know, have a coffee and a bit of a chat and just to be with the sensory impairment team, and really to meet other people. And, you know, a very good social life.

Q: Yeah, absolutely.

A: And I was having mobility training of course, so that sort of comes and goes because my sight--, if you're in a situation where it's degenerative you don't have a stable situation. And other things were happening with me as well, with the whole, you know, the condition.

Q: What did the mobility training entail?

A: Going out with a long cane, erm, trundling around the streets, you've got to learn all the kerbs, you've got to learn all the, this, that and the other. I did it, but I've had lots more as my sight's gone down. At the beginning I didn't need to use a long cane, I could get around New Malden with a symbol cane, because you'd lived here, you'd driven here, it's where you live. They came and they did adaptations to the house, i.e. in terms of tactile stuff, but I've had a lot of mobility recently because I can only now see light--, light perception. And I've got lots of swirling and interference, and life's been very different over the last three years. I've had--, I woke up one morning and all the buildings had gone so I couldn't get out to the gym, but I've had Charles Bonnet Syndrome, I've had complex and I've had hallucinations. So I had a six month period where my house didn't look like where I lived because I was having--, when I went into it, it was into medieval land, but initially in the house all sorts of funny things were happening. Should I be talking about this now or do you want to talk specifically about the Crescent Resource or the beginning?

Q: Oh no, yeah, feel free, yeah, feel free to talk...

A: My hallway's got cream walls but in my hallucinations it had bright orange with big black paint flecks all over it, my kitchen windows were swathed in huge big, erm, what would you call them? Swags and tails, it had all Laura Ashley wallpaper in there, my house turned into a 1970s, all the furniture changed, er, I remember going out to hang some washing in the garden and from nowhere were coming these--, this is going to upset me [pause, JC gets upset], it was like being in the middle of a technicolour world, all these blooms were coming up. And I couldn't go out because all the cars down the side of the house were in driveways and they were--, they'd got roof racks and they had huge trees with blooms on them. And then I started seeing flying pterodactyls and German tanks all over the roads. And then it got really bad, it went into medieval world where I couldn't see any of my streets, it was all country roads with, I don't know, big trees and castles and you had people around you who were in suits of armour and huge whatnots, so. And you can't go out and you can't function when all that's happening, and in your house all the time. I had people doing hoopla and frogs that were all lime green and orange going through the ceiling with balloons, and this all started a while ago with pylons. I was seeing pylons as my husband and I were driving along the road and I can't see out the windows, it's--, I'm living in a big world with all swirling stuff, it's all swirling and flashing and breaking up, it's a bit like if you remember Star Trek when they got into the transporter and they went from--, well, they went into sort of all flashing stuff, and that's what's happened. And I could put my hand through everything, and I can get round my house because I know where I am, I can't see my furniture, I can't see, er, people, and you know people don't understand really. I have lots of hassle about 'cause I'm not looking at people or doing what I should be doing 'cause you don't see the body language and, erm... But I couldn't go out for months because how can you go out of your front door when you're living in, you know, the time of King Arthur [laughs], and it's just--, I've been taking part in a project with a guy called Professor fytche and he's been looking at Charles Bonnet which people who've got sudden sight loss tend to get, but I've got complex so I've got all these people living in the house. It's silent, nobody speaks to you but they're, erm, it's really, really bizarre because I know what I'm seeing is not real. So I just couldn't go out, and then when I went out in June '15 with some friends I fell and broke my right foot, that was me in a wheelchair for three months. And then last year I tripped and tore my ligaments and my left foot in a boot for five months, and it just goes on and on and on. There's no emotional support with any of this, no emotional support. I went to my doctor who said to me get in touch with the mental health services, so they ring me and said Jen, you're suffering emotional distress but you're as sane as the next person, so you get nothing at all. And I got--, you get six sessions with RNIB and it's just a waste of blood time, because what I need, I think, and what we all need is just somebody once a month to sit and have a chat with and just to say how you're feeling. But you've got to be tickety-boo and you've got to have that personal persona 'cause people don't want to hear any of this.

Q: Yeah. How--, how are you feeling at the moment in terms of the hallucinations, have they--,

A: Well they've calmed down a bit, but I--, it's quite difficult not being able to see your husband and your son. We were laughing this morning, I go into rooms [laughs]--, are you in here, is there anybody here? I mean I can come in here and--, but nobody understands, none of my friends understand what's happened to me, they just don't get it.

Q: Yeah.

A: And, as I say, all through my visually impaired life, oh you look alright, you're this, you're that. People think I'm--, if I'm out with a group of visually impaired people they think I'm their social worker [laughs], you know, whatever. But it's just, er, shops, you know, nobody wants to take your chip and signature card. And I can't go out on my own anyway, I have to have somebody with me, but it's just--, it's a nightmare really. I wouldn't wish this on anybody, no, I really wouldn't. And I'm actually feeling okay, I'm not feeling depressed would you believe, I'm quite an optimistic, positive person, since I've become visually impaired I've learnt to swim, I go to the gym, I've been doing all sorts of things. But as time's going on and the sight's getting worse you're more and more in your home. Where I could've gone out and done things before locally, because I was trained to do it and I'd seen it before, I can no longer do that. I went round to the hairdresser yesterday, on my own with my long cane, for the first time in four years.

Q: Oh, wow.

A: Because I've been having lots of mobility to get me round to the station, I can't travel on my own, I have to get passenger assist everywhere I go. But I've learnt to rock and roll, I started that about six years ago, I've done all sorts of things, I've learnt Spanish, whatever, but you're always with--, every course you approach or everywhere you go, none of it is set up for anybody with a visual impairment, it really isn't.

Q: Have you done much work in terms of sort of campaigning or advocacy--,

A: Oh yeah.

Q: Can you tell me a little bit about that?

A: Well I've been up to the eye hospital with the KAB and the sensory impairment team, Carol Barnshaw, before the council made her redundant. And you talk to the eye hospital up there, because what they would tend to do is they would come out and shout your name, Joe Bloggs, and before you got off the seat they'd gone, yeah. And they're dealing with people who can't see them or people who are beginning to lose their vision, you go then, if you managed to get them back and you went into a room you're going in from a light room into a dark room, they haven't a clue. Take a seat, well you can't see the seat, it just goes on and on and on. You get the same sort of nonsense up at Moorfields as well. Yes, I've done lots of stuff, I've worked with the KAB, my main concern was I wanted to support other people who were suffering sight loss. So in my bedroom, on my little cassette recorder, I started recording how you can get benefits, who you can contact, what can you do. We then put that into paper in a publication called Who Shall Eye Contact?, 'cause I set up a group called Eye Contact. With Carol Barnshaw and three other people I rented a room at the Malden Centre and I ended up having 40 visually impaired people there. I had volunteers, I pestered the Kingston--, excuse me, Association for the Blind to get a grant, I used to organise a coach trip every three months, we'd go out once a month, we did tenpin bowling. We were going to groups and talking to them about vision loss, so we did all that. And I would go and meet people, when they contacted social services they would have a chat and tell them about me and I would go and meet them because I wanted to--, them to come into Eye Contact, I didn't want them to be fearful of anything that was going on. So I've done that, I've supported quite a few people in the community, just generally doing stuff like that.

Q: So when was it that Eye Contact was sort of developed I suppose?

A: '95--, I started it in '95.

Q: Okay. Can you tell me a little bit about what your sort of motivations were for that and what the aims were?

A: We were there just simply to support people who were going through the journey, I didn't want people to struggle the way I did, trying to find out what was going on. I thought well I know what it's like, pass that information on to other people. Erm, a gentleman that you've interviewed who runs the talking newspaper [laughs], I met him in '91 and I spoke to the community, 'cause the chap that ran it--, well he died actually, so... he's taken over now, so I've known him all that time. And he does a very good job on the talking newspaper, he's a real technical person and I am a technical bore because I listen to Connect Radio with RNIB, on the talking newspaper Brian puts, erm, a sort of weekly thing from the RNIB, Tech Talk, so I'm into that. I've got my iPhone--, the world has got better for me in terms of technical stuff when you're visually impaired, everything in my house talks, if I weigh myself it talks, if I bake it talks, whatever it is I've got it talking. I've got a thing called a pen friend which is an, erm, an audio labeller, so I would label all my--, with sighted help of course, I've got all my CD collection labelled, I've got all my herbs and spices--, Hazel

will come in on Thursday, we will--, she will type out recipes, she then records them on my Penfriend, er, they're in--,

Q: How does the Penfriend work, sorry?

A: The Penfriend is amazing, I will show you how to do that. You get a little dot and you stick it on whatever and then you actually record--, so any--, when I want to go back I just hit the pen on the tactile dot and there will be what it is.

Q: Ah!

A: It's an amazing piece of equipment, it came out about four years ago. And I've just got the Amazon Echo--, hi Alexa, good morning.

[Voice of Alexa, good morning. On this day in 1949 Albert II, a resus monkey, boldly went where no monkey had gone before, space, riding a V2 rocket. Albert jetted to an altitude of 83 miles.]

A: I just love her, I love Alexa, but I love my mobile phone, I've got Siri on there and I'm into podcasts and I'm into music--, [interrupted by Alexa!], no, be quiet girl! So everything talks and it's wonderful. Someone said to me recently if there's a time to lose your vision this is the time, because of all the audio stuff that is around. My computer--, which has cost me a fortune, all the software, again it's access software, it's Dolphin software so I can do all that. I'm pretty well sorted at home with stuff that does talk to me, the problem is, of course, getting out of your house. It would be nice to--, I remember hearing on In Touch--, which is on Radio Four, years ago, a lady saying people take dogs out for a walk, why can't they take visually impaired people out for a walk, and I thought what a brilliant idea. And I worked very hard with Carol Barnshaw round about 2000 and we set up the buddy scheme under the umbrella of the KAB. She and I have worked hard on that, we've recruited staff, we've now got an office and got the tandem buddy scheme, some blind clubs and, er, so we worked hard to do all that sort of thing really.

Q: Can you tell me a bit more about the buddy scheme, how that--, how all of that works?

A: Well, having listened to this thing on Radio Four and I thought well you've just got to get out there and help people. And then there were a lot of people with HIV and they would have buddies and stuff like that, and we started off calling it home visiting scheme 'cause Carol and I went to other--, we went to Merton and we went to a couple of others, Sutton, and we looked at what they were doing, and so we sort of cribbed a bit and... So basically we've identified certain visually impaired people, we've married them up with a buddy, the buddies all have blind awareness training, er, your buddy can come and visit you--, it depends what you want to do, once a week, might read your post--, they're not there to do domestic chores, that's not what it's about, it's friendship. Might go out for a walk, might go out for a coffee, stuff like that. You might have a buddy that goes to the gym with you, er...

Q: And is that on a voluntary basis?

A: Yeah.

Q: Okay.

A: Hmm-hmm. So we've got quite a few--, and we've got tandem buddies as well, so we've got people buddied up and it's, you know, it's a really good thing to do, it's a fantastic scheme.

Q: How many people have you got involved with that at the moment?

A: I really don't know because I resigned from the KAB because I met Metro Blind Sport in November '07, someone sent me an email and I went up to platform one at Waterloo because they were dancing and started off learning to salsa [laughs], at Waterloo in a dance studio. Then went on to rock and roll and then they said to me why don't you come, you know, and play visually impaired tennis, it's starting off in England. And I said don't be silly. So I went along and then I then got on to the tennis committee, I can't--, I used to play tennis and squash when I could see but I have to say, to be perfectly honest, it's more for the social side and a bit of a laugh and making a fool of myself because, erm, do I hit the ball, mmm [laughs], occasionally. It's--, actually, I've got one here 'cause--, [rattling sound], there she is--,

Q: Oh, okay.

A: So you've got short rackets that a child would use, you've got lower nets, so I stopped doing the KAB because I went onto the Metro committee and I've done lots of stuff for Metro as well. So I'm not sure how many people are buddied up at the moment with the KAB, but I'm going to start tandem riding again because I've just spoken to them about getting their tandem service which they are doing at the moment, they're trying to get front riders and we give them all blind awareness training.

Q: Amazing. So can you tell me a bit more about what you do with Metro Sport?

A: Well, my husband, Fred, who can see, is actually running archery, he's been running it for four years so I've started doing archery. Now, within the world of blindness you've got high partials, you've got partially sighted, you've got what they call severely sight impaired, you've got blind. Now only four percent of blind people see nothing, the rest of us would see a bit of light perception--, I get around my house which is now black inside which is not good, but I can get round because I can see the light coming in the window, so I head for the light. So you've got all different levels of visual impairment, the better your sight the better you hit the bull [laughs], most definitely. But it is good fun, it's very--, it's very good socially, so I was doing that. I've done tenpin bowling with them, rock and rolling, I've got that with a passion, I love to dance. I do go into, erm, I go with groups of visually impaired people to dance but we're in the sighted world, and that's quite good, and if you get a good dance partner it doesn't matter if you can't see what's going on, it's how the lead is, so that's good fun. And we've gone into--, all of my girlfriends and I, we've gone mad and we've been away for weekends and we've got--, with Metro, and we've bought all the retro stuff, I've got lots of '50s circus skirts, stilettos, dancing shoes, fans, the works, you just--, you get into the part. And we've done a couple of wall to wall weekends, 50s, there's been about six of us who are all bumbling around there in the dark, or near enough [laughs]. But you tend to get on a bit better with high partials because they're helping you out really. So what have I done with Metro? Erm, well, yes, archery, dancing, tennis, er, tenpin bowling, a bit of swimming, they do all sorts of things like that, they're very, very active. I haven't done the cricket [laughs], I don't fancy that, but yeah, and very good socially as well really, just meeting other people who are in the same boat, so you don't have to explain yourself constantly.

Q: What motivated you to want to learn to swim?

A: Well I was brought up in Ireland and if you open my parents' front door 50 yards in front of us was the sea, and I never learnt to swim because the Irish Sea would freeze you to the point of [laughs]... And I just thought to myself I quite fancied it, but when I went to school with Nick one of the mums was a swimming teacher. And I went to the Malden Centre and it took me a year and it's the best thing I've ever done, I swim three times a week. And I used to joke, if the High Street ever got flooded, now that I can't drive I could always swim down it [both laugh]. And it's lovely, I just adore it, and I'm swimming in there, I could maybe sort of a way see a blob of a person if they got near to me, but when I woke up three years ago and the world changed, I'm swimming and I can't see anybody in the water with me, I can hear them, I can hear the splashing and all the rest of it. And someone said to me a while ago you're incredibly brave, and I thought oh I hate people saying that, but now I think yes, I am incredibly brave [laughs].

Q: [Laughs]. Absolutely. Was--, was provision put into place when you were learning to swim to--, to be able to support you?

JC No, it was just Chris and I, a mum from school.

Q: Really?

A: Hmm-hmm. I paid privately. Had to do a one to one 'cause I couldn't join a class, 'cause that was--, well I just couldn't cope with that. So I used to go on a Wednesday for half an hour and she was in the water with me and she swam in front of me but backwards, teaching me to tread water and everything, it took me a long time to--, and that, you know, and I remember she said to me about--, I learnt in '95 and about ten years ago she said to me--, she just happened to be in the centre one day and she's taught hundreds of people to swim, and she said--, she popped in and she said there I was backstroking up the pool and she went go on there girl, it's been worth everything [laughs]. Yeah, and she said that meant more to her than, you know, teaching kids or other people. But I do love it, it's just the most wonderful thing.

Q: That's an amazing achievement, you should be very proud of that.

A: Mmm. Mmm, it's good.

Q: So what--, what work do you do at the moment in terms of support within the blind community?

A: What do I do at the moment? I haven't done much really, because I couldn't leave my house, I couldn't walk because of my broken foot and my torn ligament, and because of all the hallucinations I was experiencing. I talk to people on the phone, er, I was supporting a couple of elderly women in the community who are visually impaired up until this happened to me three years ago. So, erm, haven't really been doing anything, I'm--, I've been involved with Sight for Surrey because they--, I've had some computer lessons which I'm paying for privately, my husband had a real struggle trying to get me help. He found this guy on the internet, Gary his name is, he's brilliant. He's been here five times, but through him I've joined his Apple club which he set up four months ago, so my husband's driving me down to Fetcham in Surrey and I'm learning a lot about the iPhone now, because I drive it by speech. Just really being with other people who are visually impaired, chatting to them, it's really good fun. My husband came into the room last week down at Fetcham and he said--, there were 14 people in there and the laughter and the fun that was going on, and that's just incredible.

Q: Obviously technology is incredibly important to you like you've mentioned, have you been involved with sort of testing any new equipment?

A: No.

Q: Oh. Yeah. Do you know who does do that, do Kingston Association for the Blind, do they sort of trial things or is it...?

A: Er, just recently they've had a bloke from RNIB come along and look at an iPhone, and they've got one of the girls in the office who's not actually--, she's not a trained trainer but they're starting a thing called Tea and Tech and I think they've run two sessions, where you go down--, but I have to say, to learn any of this you need to be on a one to one. Because people will be at all different levels, they would have different learning skills, you know, people learn in a different way. And you can sit in a class but people are going to be talking, it's very, very difficult. At Fetcham you're put with another blind person who knows more than you, so you're learning from each other, I in turn will, when I go down the road a bit further, will start helping other visually impaired people that come along that won't really know what's happening with iPhones, it's just sort of teaching each other. Gary's been very, very good, he's visually impaired himself, he

does the computer lessons, he's employed three days a week but he is absolutely brilliant because he'll come here and he started me off, and he backs everything up on an email which my computer will read to me. Which is the way to do it.

Q: Excellent. So I'm not really sure if you can answer this, so--, well, so at the moment you don't receive any support from Kingston Council in terms of access to any social provisions? Okay. Do you have any--, do you sort of keep in touch in terms of what the sort of current state of the disability support system is?

A: Not really, because what happened was when--, my husband was made redundant actually, in 2011. And I had--, I had a lovely PA here, who was a gorgeous Polish girl and she was with me for five years, and she--, this was '09, she married and moved to Lincoln. And it's very hit and miss with PAs, I got an Italian girl that was in my yoga class who came and she was an absolute fruitcake, she was coming when I wasn't expecting her, she wasn't turning up when I was, she led me a merry dance, meeting me in Kingston, I would get on the train, I'd meet her at Marks and Spencer's 'cause I could just about see enough to get to Marks with my mobility training, and she would leave me standing there for an hour and a half, that's terrifying when you can't see who's around you. So I spoke to KCIL about getting rid of her, which I did, I gave her notice and we paid her some dosh. We decided, 'cause I'd had about three or four people after she left who were just messing me about, my husband and I decided we'd do it on our own, so I've started privately getting someone to help me with the admin. I do need some help but when you've experienced some of the nonsense I've experienced it makes you very, very wary and I also had quite a bad experience with KCIL with one of their people that were meant to be coming to help you recruit, so that sort of put me off as well. First of all I was getting bundles of filled in application forms which I couldn't access which had got nothing to do with my requirements at all, and the chap that was running it at the time, most unsatisfactory. He did actually come here with a girl that--, he turned up late and I hadn't a chance to go through the form with him. He didn't tell me what her background was and I, after the event, thought it was very relevant. She was in a halfway house, she had mental health problems, she came from a very violent background, I knew nothing about this, I had her in my home and on the first day she was here she started to discuss self harming, how she was fascinated by knives, what her boyfriend had done to her, knocking her about and all sorts. And I was so terrified I went up into--, I said to her excuse me a moment, I'm just going into the garden, I went up to the top of my garden and I phoned my husband on my mobile phone. That was all hidden from me. She had a very violent background and I'm a very vulnerable person and I just couldn't cope with it all, so, you know. So there are--, things have gone wrong really. So I don't know what's happening at the moment, I do need to recruit somebody but who do you recruit? What sort of an advert do you put in? You don't want to say visually impaired woman requires some help because you could get all sort of potential nutters coming in, and I've experienced three or four of them and I don't feel happy about that. I've got Hazel whom I've known for years who used to work for the KAB and she's great, but that's simply my paperwork, it's not help around the house. [The Polish girl] was brilliant but she's left and she's got children now so she's a no no. I just want a sensible, respectful, intelligent, normal person to come into my house to help me, I don't want people with lots of emotional baggage or behavioural nonsense, and that doesn't seem--, that was not very well screened.

Q: Okay, yeah, yeah. What changes would you like to see made in terms of sort of access to--, to services?

A: Well, I don't know what the assessment situation or anything is any more, I really don't know. I've had loads of hassle for the last year with the Department of Work and Pensions with all this moving from DLA to PIP, it's made me very ill. My stuff should be given to me in accessible format and in December '15 I got a phone call at quarter to five at night from the DLA people to say as you haven't responded to any of our letters we're stopping your benefit tomorrow and I said I haven't had anything from you. They're meant to send it to somewhere to be put into audio to get to me, none of that had been done and at that point they said we're shutting the office at half five, you've got 45 minutes to ring this number in Liverpool and apply for Personal Independent Payment. I was home alone, I couldn't take the number down, I

couldn't read it back, I couldn't make that phone call. Luckily for me my husband turned up at a quarter past five. I was forced into having to apply for a PIP, I then had to fill in a form which took 12 hours, I had to get all my medical stuff and everything else. I then had to go through the humiliation of going to an assessment centre with a woman who could hardly string a sentence together in English, who showed me no respect, didn't tell me who she was, sat on a computer for one and a half hours and asked me the most disgusting questions like can you take yourself to the loo, can you wipe your own bottom, all sorts of stuff all about--, as we'd already filled in the forms, about cooking, all sorts of nonsense. They didn't want to ask can you gather your own food [laughs], it's just the most disgusting thing been done by the government. I've spoken to some of the social workers about that, it's just disgusting, the whole thing is. And I don't know what the assessment centre with social services--, or, you know, the process is any more, but it sort of puts you off.

Q: Yeah, I can imagine, yeah.

A: Hmm-hmm. It took three months to get my PIP through, and I wasn't well for three months, I was just a nervous wreck, it just completely throws you, pushes you into the ground when you actually need help and support. You don't need to be challenged about can you take yourself to the loo; in my own house, yes, in a public place I can't see, so how could I be able to find the toilets [laughs], and all this nonsense, you know?

Q: Yeah. Mmm.

A: It's just pretty gruesome--, the whole thing's pretty gruesome.

Q: Yeah, absolutely. On a positive note, you have done some really amazing things, been involved with some really interesting schemes. What would you say is the thing you're most proud of--, what's your proudest achievement?

A: I think my buddy scheme and I think setting up Eye Contact to help other people, but I think learning to dance and meeting other VIs and encouraging quite a few people I've met who are visually impaired to come and learn to dance with us really. I try and do that, I try and--, when I do meet people I find out what they don't know and I like to impart the information. I've also--, up until I broke my foot I was a volunteer with Health Watch in Kingston, so we were going round doing, you know, assessments at the eye hospital and just talking to other groups of people. I'm trying to think of people with blind awareness, it's, er, it's pretty tough going because you get barriers or gateways, and there's an awful lot of barriers, even going into the library. I haven't gone there for years because you go in and you can't see, you've got a long white cane and the person on the desk doesn't speak to you, so you're ending up saying is there anybody here [laughs]. And you'll probably not get a lot of help, hopefully things have moved on a bit, but... I would love to get up in the morning and--, I'd love to get up and go out and people would say as I went into a shop good morning, how can I help you? Instead of refusing your payment or not understanding you can't see them and coming out with all sorts of nonsense and, er, it's never ending--, never ending. You know, I got to the Malden Centre, we gave them blind awareness training with guide dogs, the staff keep changing. All I want is when I approach the desk is for somebody to say good morning, I'm Bethany [laughs]. So I'm really, really working hard on that, I've done a lot with them. I keep on their case because it's very, very difficult. And last week when I went in I said to them--, because nobody spoke, I said is anybody there? Oh yes, I'm here. I said right, do me a favour, shut your eyes and don't open them until I ask you. I said what am I doing in front of you? Don't know, can't see. I rest my case. I said right, when I come in here tomorrow I want you to say such and such. The lifeguards--, I got a swimming hat from British Blind Sport, bright orange with a big shaded eye symbol and it says on it 'British Blind Sport, visually impaired'. None of them knew what it was, one of them thought I was a representative of The Big Brother House [laughs]. You've got to laugh, I do have a laugh amongst all of this, I mean sometimes some of the things I say, I mean I just think these people are mad, you know.

Q: [Laughs]. For goodness sake.

A: I know. I've also--, my girlfriend had cancer and I'm one of her chemo buddies, and I was up at the Marsden in Fulham and I went up to the nursing station because she was having her chemo and I needed to go and have a coffee, I wanted a volunteer. I walked up to this thing and I said hello. And before I got any further I was greeted with oh, I see you've got one of those Nordic walking poles. And I said excuse me, have I--, is this the nursing station? Yes. Are you a nurse? Yes. Are you blind? No. I said well I bloody well am, that's why I've got this long white cane in front of me, you know? I get further down to have a coffee and the woman that's bringing me back, the volunteer, she thought I was a Nordic walker. But I had it two weeks ago in John Lewis in their lingerie department, where I'm standing there with my husband and I said to the girl I'd like, you know, [whoop], took me into the changing room, fitted me with a bra. I'd folded the cane up in front of her and put it down there, and then she said well what do you think, have a look, how do you think that looks and what about the colour? And I said well I think it's a bit--, just a wee bit, you know, big here. Oh, but what does the line of the bra look like? And I said to her are you winding me up? She said pardon? And I said excuse me a moment, I undid the thing and I said to her you've walked in with me, what the hell do you think I'm doing? I'm visually impaired. And she said to me I thought you were a Nordic walker, and I thought to myself why has she only got one stick, this is 2017, give me a break.

Q: How many Nordic walkers are there? [Laughs].

A: I don't know, but my husband was golfing with all his colleagues last week, Wimbledon Common, and he said there were a whole crowd of Nordic walkers and he's relayed this--, look, there's a load of blind people walking across the common [laughs].

Q: [Laughs]. Oh my goodness.

A: Yeah.

Q: Yeah, I wouldn't have even known the term Nordic walker, it's--, oh my goodness.

A: Well there you are, get all this...

Q: Wow, yeah.

A: Yeah, it's a--, it's a hard old, you know, it's a hard old ride, this, every day. I never get a day if I--, when I go out, that I don't get some nonsense thrown at me. You get very nice people--, people on the trains and tubes are great if you get to the station, Joe public, they're tremendous, jumping up and giving you a seat, you know, doing all sorts of stuff. But you've just got to keep your wits about you. I now have to say all the time this is a signature card, I sign. Marks and Spencer's, I've written to the CEO, I've done all sorts of stuff. I never meet anybody who will accept my payment.

Q: Yeah.

A: It's all down to staff training.

Q: Absolutely, yeah. Yeah, incredibly important.

A: It really is. But can I say something about KCIL?

Q: Yeah, of course.

A: Right, okay. I stopped going to their AGMs and various things 'cause I go with a load of VIs. The last one I went to was down at King's Meadow, I spoke to the CEO at the time, can't think of her name. But

basically they've got a buffet, well you can't see any of that, there was no help there at all to help me with the food, but I went over to her and I said please go round the room with your names, and this is year on year on year on, because I can't see who's here, not just me, we want to know. And again, she started the meeting. So I stood up and I just said excuse me, I'm Jennifer, I'm visually impaired, you--, I did ask that you go round the room with the names. It'll take too long. I said it'll take you two minutes, you should be building it into your agenda and I said I'm not going to sit down until you do it. Now they had a microphone so I said I want--, all you have to do is take the microphone, I'm Jo. But several people in that room that I couldn't see were visually impaired and they all said well done, because we can't see who's here either. And other people, wheelchair users or whatever, they were saying well done. I've had it year on year on year on and I've actually stopped going to the AGMs because of this happening. Years ago even the Mayor said to me oh no, we haven't got time, you're going to have to sit down. I said well I'm sorry but I'm not going to sit down, I'm not sitting down until you go round the room, I said tell me what the topic here today is? Access. I said bloody access. I, you know, you know, you're stopping me from accessing this meeting, it just goes on and on and on and on and I'm not alone in saying this, so...

Q: Yeah.

A: We got pretty fed up with it so I just thought, bother it, I'm not going to bother.

Q: Yeah, I completely understand, yeah.

A: Hmm-hmm. Yeah.

Q: I think that is all of my questions, but was there anything else you wanted to mention that I haven't asked you about?

A: Erm, not really. Er, not really. It's just, er, hopefully they've moved on--, hopefully they've moved on.

Q: Well hopefully this project is helping with that as well.

A: Hmm-hmm. Yeah, because I certainly haven't seen it. It's all [snap fingers], well, it's all wheelchairs, you know, it's very, very difficult if you're hearing impaired or sight impaired, but that's why I stopped going, because I couldn't access the meetings, so I haven't been for a long time. But I might reconsider 'cause Robert told me things have moved on.

Q: Okay [both laugh]. Thank you so much, Jennifer, I'll stop the tape there...

**[END OF RECORDING – 00:58:12]**