

ORAL HISTORY EXTRACT TRANSCRIPT

'Fighting for our Rights' project

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Extract 1: losing sight

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.

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--, that was it, that was the end of my--, a normal life if you like.

Extract 2: Crescent Resource Centre

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. 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. 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, very good socially.

Extract 3: Eye Contact

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. 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 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.