

ORAL HISTORY RECORDING TRANSCRIPT

'Fighting for our Rights' project

Surname	Stuart
Given names	Christine Elizabeth
Date of birth	1944
Place of birth	Gorseinon, Wales
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Name of interviewers	Uloma Paris, Jen Kavanagh
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Q: This is an oral history interview with Christine Stuart, by Uloma Paris, on Friday 19th May 2017. Also present with me is?

Q2: Jen Kavanagh.

Q: The interview is taking place at Christine's home as part of Kingston Centre for Independent Living's Fighting for our Rights Project. Please could you state your full name?

A: Christine Elizabeth Stuart.

Q: What is your date of birth?

A: [REMOVED] 44, you're honoured, [laughs].

Q: Where were you born?

A: In Wales, Gorseinon.

Q: What were your parent's names?

A: Myra Elizabeth Jenkins, and Norman Henry Shaw.

Q: What were their professional?

A: Well as you would expect my mother was a housewife, and my father was a photographer.

Q: Where did you go to school?

A: In Wrexham, North Wales.

Q: What age were you when you left school?

A: School?

Q: Yes.

A: 18.

Q: Can you talk me through what you did between leaving school and when you had your son Andrew?

A: [Laughs]. Yes. I went to university for three years and got a maths degree. I went to, erm, that was in Aberystwyth, on the west coast of Wales. Then I did my post graduate year in teacher training or education at the Institute of London. So I was based in London. Then 1967 I went to Broxbourne in Hertfordshire and taught for two years. And then in '69 I took the big plunge and went to live in America to study at Princeton Theological Seminary. Not Princeton University, Princeton Theological Seminary, which was a complete change of scene 'cause I was doing theology and religious studies. That's where I met my husband. We came back here the summer of 1970, and we got married in North Wales. We then went back to America. We both finished our respective degrees. And at the end of his degree, and at the end of the year of where I'd been working in a church, erm, we came back to live in Britain. So we came back not knowing what we were going to do. We decided we'd come back and we were going to have a month pretending we were on holiday, not worrying about work. And the day the month ended my husband got a letter saying, we hear you're in the country, would you be interested in having a meeting with the moderator of the URC in Wales? Because my husband is a minister. And from there the rest is history I suppose. Very unusually he became Assistant Minister at the City Temple in London, which is quite a well known non-conformist church on Holborn Viaduct. So for three years we were church mice, we lived on the top floor of the City Temple. The reason it was still there, it was bombed out during the Second World War, but the front of it remained standing so they had ancient rights to the ground and could rebuild there. So it was the only English speaking non-conformist church in the City of London. And I have to say that because with great pride the other non-conformist church was a Welsh speaking chapel. And being Welsh that was important to me. So we had three wonderful years living in London. But during that time I couldn't do anything easy. I got a job out in Enfield and I went back to teaching maths. So I did that for three years. At the end of three years, er, my husband was called to a church in North London, initially I thought I'd stay put in Enfield, and then I decided very last minute because with teaching you have to give in your notice at half terms, to apply for a couple of jobs fairly near where my husband was going. And to my amazement I got both jobs on the same day, and the job I took was as head of maths in a comprehensive school in Bushey. The school where George Michael went. I eventually became Head of Sixth Form as, yeah. Actually not eventually, after one year I became Head of Sixth Form as well as Head of Maths. And my claim to fame is that I told Andrew Ridgeley really he was a waste of space and there was no point in carrying on with his education. And I hear he uses that in interviews against me all the time. George Michael, on the other hand, was actually a very intelligent boy, and I told him to stick with his A levels 'cause this pop music will get you nowhere. How wrong can you be? His name at that time to us was Georgios Panayiotou. And it was during that time that I became pregnant, and that's where Andrew comes on the scene. So we were living in North London in Northwood. Andrew was born in Northwick Park Hospital. When we talk about hospitals with dubious character, Northwick Park has certainly been well known in the news, and I can testify that it was far from being a model of excellence. That's the end of the first stage. That's got us up to Andrew being born. Do you want me to take it from there now?

Q: What year was Andrew born?

A: 1978. The day after Louise Brown, the first test tube baby was born. So it was quite, again a significant time because you remember that very, very closely. What do you want me to do from this point?

Q: Please could you explain Andrew's condition, and when this first presented itself?

A: Oh brother. I had been hospitalised for high blood pressure. I managed to get out the week of Wimbledon because according to my husband I soft talked the doctors, saying all my life I'd wanted to watch Wimbledon and here I was stuck in hospital not able to watch Wimbledon. So wasn't it a bit of a waste that I couldn't see what I wanted to? So they let me go home for the week. I was clamped back in irons straight after 'cause my blood pressure was sky high. So that's a little bit of background. So I actually was induced to give birth to Andrew. And the induction was relatively slow and steady, and nothing really to mention until I had an epidural, and she upped the epidural medication, which may have camouflaged things. For some unknown reason, she was a senior midwife, she disconnected the baby from the monitor about an hour before he was born. Yes I can tell by your face you can already read what's happening. So for the most part she just carried on, and there was one point when she was listening for the heartbeat and I realised very quickly no monitor had been seen at this stage that obviously, she couldn't find a heartbeat. So she very quickly at that point called an obstetrician, who happened to be the obstetrician I'd been under while I was in hospital, so I knew her well. So she was very surprised I was in any predicament whatsoever. Got wheeled along for a delivery, and the obstetrician immediately said to the midwife, "Have you called for the paediatrician?" And this was before Andrew was born. The midwife actually said, "No, why did I need to?" And the obstetrician literally just said, "Get the Paeds." Andrew was then delivered by forceps with, needless to say, the Paediatric Team in attendance. They immediately started working on him, which I knew wasn't good. So I suppose there was a heightened awareness on my part from the word go. Because I had a good relationship with the obstetrician she immediately said to the Paeds, "Let mum hold him." So I just said, "Oh come on Andrew Miles, get a headache." And everybody was startled because it appears parents don't immediately identify with a baby by giving the name. And erm, they all said, "Oh he's got a name?" I said, "Yeah of course he's got a name." [Laughs]. And until he was born we didn't know if it was going to be a boy or a girl, so actually we'd had more discussions about a female name, which was going to be Welsh, erm, than if it was a boy's name. We hadn't argued at all over the boy's name. And it was strange because immediately he had an identity. He was whisked off to intensive care. I suppose if you want to know when did anything present itself I would say at the point where I believe she could not hear a heartbeat. And I think they were a bit gobsmacked that we were as in tune and aware of what was going on as we were. Once he was in intensive care I discovered I was incarcerated in the ward because having just given birth they wouldn't let me go up to see him. My blood pressure went through the ceiling. Erm, and the first night was extremely difficult. But early the next morning, I don't know if Bruce came in and took me up, or somebody took me up, but I had to be taken up in a chair. So at least I saw him then. Erm, I was in hospital, he was born on the Wednesday, and I'm 99 percent certain I came out on the Saturday. So there was the Thursday and Friday when I would go up to intensive care. And certainly on the Thursday I think I was taken up. And on the Friday I think I was able to walk up. so I took them a little bit by surprise 'cause they were running around like scalded hens gathering together equipment to take a baby for a scan. And the equipment included resuscitation equipment and oxygen, and things like that. So when I walked in they looked at me and I said, "I've come to see Andrew." And they said, "Oh we're just taking him down for a scan." And I think it was the last thing in the world they'd wanted me to do was walk in at that stage. But obviously, there had to be honesty. After the scan I think I should have been a lot more demanding as to what they had found. But in a casual conversation with a doctor in the corridor of intensive care, we were like ships passing in the night, he said, "Oh I think I've found on the monitor the point where Andrew should have been a caesarean." So I looked him straight in the eyes and I said, "Are you aware he was disconnected from the monitor an hour before he was born?" And it was as though I'd hit him in the face 'cause he was totally unaware. He thought those scans went right up to birth. And they sure didn't. We did get feedback from them about the scan, but the scan was, it's a very small area of the brain affected, we will have to wait and see if there is any impact. They weren't honest. He had, obviously, breathing difficulties, he had swallowing difficulties. He couldn't drink a bottle, although on one occasion he did. And that startled everybody. And I said, "Oh he's as stubborn as the mother," and we had great laughter at that because they said all the negative attributes are normally put down on the father not mother, by the mother. So you know funny that I said, "Oh he's a chip off the old block, he's as stubborn as

I am.” And one nurse just said, “Why don’t we try the breast?” And fortunately it’s a different sucking and swallowing mechanism from the breast than from the bottle, and he was able to take milk from the bottle. So when I went home on the Saturday they gave me a machine to express the milk so that he could drink my milk when I wasn’t there. Of course the day I was leaving I was literally on the way out and going to go up to see Andrew, and a nurse came running after me and said, “Oh I’d better take your blood pressure before you go.” She took it and her comment was, “Oh my god I can’t put that down otherwise they’d never let you go,” and let me walk out completely without anything else. Which when I look back I go, time bomb ‘cause I could have so easily had a stroke. And she actually would have allowed it to happen. So Northwick Park it’s not a favourite of my hospitals. And when I hear of incidents at the hospital I look back on our time and think, hmm, should we have acted differently? So while Andrew was still in hospital, and he remained there until about the middle of August. Erm, really the information that a very small part of the brain had been damaged and they had no idea how it manifested itself. As I say, because of the sucking, swallowing problems I really think that that was an outright lie. That was all we were told. We took him home and immediately went down to Wales to be with my parents, and took him to the beach. And we have a lovely photograph of that first day on the beach, all wrapped up very warmly in August, in South Wales. But South Wales is a very important part to us. Right that was the August. Initially I was advised not to go back to work so that I could bond with my child. And I looked at people as though they were crazy because we were well and truly bonded from day one, and there really wasn’t the need. But I heeded their advice and took off till half term. Nobody told me the correct channels so I lost maternity pay because it wasn’t handled properly. But I went back in the end of October, early November. And really worked the remainder of my working life. Partially because a very wise Paediatrician at Northwick Park strongly advised me to work ‘cause he said, “You are not going to get fulfilment in your life as a mother. And you need fulfilment somewhere.” So, do you want to move in the other room because of the rain?

Q2: Possibly, yeah. I might just pause. Okay.

A: Once I was working we were going for physio on a relatively regular basis at Northwick Park Hospital. And there were two therapists we saw, a physiotherapist and an occupational therapist. The physio was delightful, and on one occasion said--, oh no I may have got this wrong, sorry, I’ll go back a line. Yeah I will go back a line there. we were seeing the Paediatrician and he set up an assessment by the physio, and I think it was something like the 1st of December, which for me happened to be a staff training day, an inset day. So I went with Andrew for the assessment. And once the assessment had taken place it was becoming, to me, obvious to a blind man that there was something physically wrong. Other people were trying to convince me that there was nothing wrong, and I would just have to say, “We’ll just have to wait and see. We know there’s damage, we’ve just got to wait.” Incidentally, the Paediatrician, we were in an appointment one day and in walked the Obstetrician who I had been under. And she and I had developed a very good relationship, and she was really startled. And she actually said in front of the Paediatrician, “What are you doing here?” So she was actually the doctor who delivered Andrew. And I looked at the Paediatrician and I said, “I’ll leave that for you to explain when we’ve gone.” ‘Cause I felt there was no point me saying anything. But I have a feeling she was enlightened pretty quickly afterwards. So the assessment took place at the beginning of December. Now that would have been August, September, October, November, December, five months. From that point we were seeing the physiotherapist maybe every week. So after about three weeks she said, “Have you had any feedback from the assessment?” And I said, “Well no we haven’t.” And she said, “Well I really think you ought to request it.” Again memory is hazy, but I think it was the Friday night before Christmas that we met with the consultant, my husband and I. And friends looked after Andrew so that we didn’t have to take him with us. And we were eternally grateful that we were both there because I think what one heard the other didn’t necessarily hear, and vice versa. So between us we were able to put everything together. So the term that hit me was spastic. The term that hit Bruce, who’s American, was cerebral palsy. So afterwards we were comparing notes and I think we got a pretty full picture of what was communicated to us. But really it was, again a question of waiting and seeing. No prediction of where the future would go or anything. I phoned up my parents, and I was extremely close, especially to my mother who had been lame all her life, so I had lived with disability as a child and as a young adult. And she had a terrific empathy with Andrew, and a

terrific need actually, to be with him. When she was away from him she was really quite scared. When she was with him she felt totally calm and reassured. So there was an element of that. And I rang up and said, "Any chance of you coming up to London for a coffee tomorrow?" And my mother said, "You must be joking, I'm getting ready for Christmas. What on earth is the matter with you?" And then she quickly said, "Have you had the results of that assessment?" I said, "Yeah." And she said, "We'll be there." So they literally came up for the day, and we were able to talk to them face to face. But that was an interesting start to Christmas. So it was most probably the most interesting Christmas imaginable, and one, which we will never ever forget. So I suppose that's the point where we actually found out clinical diagnosis. So the next question?

Q2: Well, could you sort of just talk us through those early years I suppose with Andrew, and what that was like? Sort of how things developed.

A: The early years? [Pause]. Right. Obviously, I was working. We had a day nanny, her name was called Ann, and she lived locally, and she was delightful, just a young woman. But she, yes I mean she was just delightful and we could trust her 100 percent. However, at the Easter, and it's not a time you will remember, but we had an exceptionally hot Easter where the winds came from the Sahara. And it was incredibly hot. And again my parents were up, and we went over to Windsor and we saw signs for polo, and we thought, oh that will be fun to go and watch. And we had a car accident. With Andrew in the car. That night he had a huge convulsion. From our perspective it was the first convulsion we had ever seen. And he was hospitalised in Mount Vernon Hospital. Where in April he was virtually stripped naked, had the windows wide open and a fan blowing to keep his temperature down and under control. 'Cause there was a question mark whether or not it was a virus. He had a lumbar puncture. Hearing his screams was not funny. But I suppose that started the chain of very regular check ups, especially to do with epilepsy. At some stage he was put on the anticonvulsant Epilim, which I think is sodium valproate, but I'm not sure. And at times that got tweaked. And I can't remember whether it was straight after that event that he was put on it or whether they waited for another convulsion. Eventually we were given medication, which we could insert into the rectum, which would stop a convulsion. And if it didn't stop it then we had to dial 999 and get an ambulance. So that happened. The end of that first summer the day nanny left and we had to employ another nanny. And this was a person called Rita. So by this stage Andrew was one years old. He hadn't been a good sleeper. He wasn't supposed to be able to eat, but had stolen a cabbage leaf in a supermarket once and promptly eaten it. Which the consultant informed me, "But he shouldn't be able to do that." And I said, "Okay, you try telling him he shouldn't be able to do that because he does it." And you know once we got onto solid foods the consultant would say, "But he shouldn't be able to eat that." And I would say, "But he does." And that was the pattern. The pattern went on with the Paediatrician where we'd have appointments, and usually towards the end the consultant would say, "What questions do you have?" And on one occasion I very directly said, "I have one question and that is what question have I not asked?" To which he replied, "And that's the question." And again, did not answer it. So there were lots of things, would Andrew be able to walk? Would Andrew be able to talk? Were left totally hanging. Even the physio thought Andrew would be able to walk 'cause he was incredibly highly motivated. But unfortunately, the lack of coordination really came in badly and he had incredibly variable muscle tone, which they noticed from a very early stage. So he could be tight as a drum one day and then very floppy the next day. And we still get that 38 years later, terrific variation. And there's no rhyme nor reason to it. So we had a new nanny. For some reason we started going to a place in North Watford. I'm not sure if it was every day or occasional days, or if it was once or twice a week. It was called The Spastic Society. And I still rail my eyes over this because times have changed a lot. Centre. They were much into the [inaudible 0:26:47] model. And looking back I realise Andrew was a total square peg in a round hole because Andrew has always been, I will do it my own way. So to try and get Andrew drilled into doing a specific way, they were trying to get him to get to a sitting position when he could already sit on the floor if you put him, and keep his balance. And he had developed a way that he could roll over, get onto his knees and get into a vertical, well a sitting position. So they were trying to teach him how to sit properly and one day I said, "Are you aware he can actually sit? Are you aware he can get himself up?" And they said, "No. How can he do that?" I said, "Okay, well give him a chance and let him show you." So I said, "Okay Andrew, get

yourself sitting.” So he did, and they were absolutely gobsmacked. So they were trying to go through everything he innately had already been teaching himself to do. Actually he was one year old and we were on the beach in South Wales when he first sat for a long time unsupported on the beach. And I actually said, “I’d better take a photograph of this. I didn’t know he could do this.” But of course the sand was moulded around his body. And it took about another three months before he could sit on a hard floor. But he would literally look around the beach, and he would look at what other people were doing and then he would model his behaviour on what he was observing. And to actually watch this thought process going on was really quite startling 'cause you could literally see it going in and think, right I'm going to do that. And so he just didn't fit in with this very rigid regime at the Spastic Centre. So we really came, er, to I can say an agreeable point of departure, but we did say farewell. And they were highly divisive and unpleasant. Fortunately for one feedback session my husband had come too. Bearing in mind I was at work, so it was the nanny taking him not me. And I would go there after work and pick them up. But I was somehow responsible that they weren't getting there on time, despite the fact that the nanny had to take two buses. She had to walk about a mile then take two buses to get there, so it was a heck of a journey in a normal pushchair, which was far from designed for making journeys like that. 'Cause that was in the day buses, you didn't have ramps or anything like that. And they started really verbally attacking me, and fortunately my husband was there. and my husband is nobody's fool, and very quietly said, “I've been sitting here observing, do you realise what you've been doing during this interview? You've been bullying my wife.” And suddenly the whole atmosphere changed. Because being on the receiving end you can most probably guess what's going on, but you're having to have your wits about you all the time. So that was a very, very bad time in our lives. Do I wish Andrew had been more conformist? I suppose I do 'cause he might have got a lot further. But Andrew has always been, I will do it my own self. Fortunately for us we lived in a local authority where they took children at a special school just down the road from us at age three. So Andrew actually started to go to school, and it was a wonderful time because he loved being with other children, the teachers were wonderful. They rang me up one day really excited, ‘Andrew’s just told us to go and mind our own business. We were intervening between him and another child squabbling in their own way,” bearing in mind Andrew doesn't speak. And he got hold of his communication book, which they'd developed, and he had told them, “You go away and make paper.” In other words, go and cut up paper and do your preparation, but leave us to it. And they were over the moon and delighted. And that really was a wonderful time. Erm, he had a very good buddy called Mark, who could talk, and together they played snooker. And Mark was a real snooker addict. Now Andrew has no coordination so how he played snooker is another matter. But they were very concerned at one time about his hearing. So I said, “Are you really sure you think he's got a hearing problem?” And they said, “Well why?” I said, “Well actually his hearing's very, very acute. He'll lie awake at night and the moment Bruce puts his key in the lock he'll go to sleep. He's been waiting for that small sound to know Dad's home.” If we'd known that we would have put the key in the lock at seven o'clock at night, but we never did, and it took us a long time to work it out. So I said, “Okay, I'll come in.” So I was in one corner of the room and they were in another, and Andrew was way over the other side of the room. So I very quietly said, “Andrew would you like some chocolate?” And his head turned very, very quickly. And I said, “Do you think he's got a hearing problem?” And they looked at me, and I said, “Do you think it might be selective hearing?” And they said, “Mm.” But needless to say he went for loads of tests and there was nothing with his hearing. Because I think they were just wondering if there was a hearing difficulty, which meant he couldn't speak. But unfortunately it was far more a breathing problem, and sucking and swallowing. Er, actually this comes to a major break point so lets stop at that point and I'll try and gather my wits for the next stage.

Q2: What was the name of that school that he went to initially?

A: Pardon?

Q2: What was the name of the school that he went to initially?

A: St. Michael's.

Q2: Okay.

A: It's no longer there sadly. But it was wonderful. Right, at that point my husband got called to a church in Sevenoaks, and we decided, well Andrew's very happy at St. Michael's, do we really want to move? Lets go and look at the schools down there. And there happened to be a school for physically disabled very close to Sevenoaks called Valence School. We went to look at it and we looked around it, and the headmaster was extremely pleasant and welcoming. Bear in mind Andrew was three years old. And on the basis that okay there would be an appropriate school my husband accepted the call and we moved to Sevenoaks. As soon as we got to Sevenoaks we discovered the school didn't take children as young as Andrew. So actually we were removing him from a school to nothing. I was still working in Hertfordshire, so I was going back to Hertfordshire every day. Mainly to see my A level classes out. And erm, we decided very unorthodoxly that Andrew and I would move back to the area we were living in in the January on a Monday morning, and on a Friday evening we would go home to Sevenoaks, so that he could carry on going to St. Michael's. St. Michael's were perfectly happy with this. They just presented Kent with a bill. Surprise, surprise when Kent got the bill they decided it was cheaper to put him in the school. Albeit they didn't necessarily have provision for him. So at the Easter he went to Valence School. And they employed a remarkable man, and the name might mean something, his name was Fergus Anckorn. During erm, the celebrations for the Second World War he was featured on television 'cause he had survived Japanese war camps, and he became quite a feinted person. And in fact it was the name came up on the television screen and I said to Bruce, "Why is this name familiar to me?" And Bruce remember who was living in Sevenoaks, so he had dealings with the school, whereas I was by now working in Sunbury-on-Thames, but I was still travelling along way. And he was his, Andrew's personal assistant. And he did magic tricks, and he has written a book called *Survive by Magic*. But he did all sorts of things like that with Andrew, and they were very, very close. He also had a dog, so would take Andrew and the dog for walks in the beautiful grounds of the school. And Andrew absolutely adored this man. And we came to September and there was no Mr Anckorn. So Andrew was now old enough to be actually at school. And the first year he had a really good, nice teacher who got quite a lot out of him. And tried to use the system of communication called Bliss. And the first year there really were no problems, the second year there was a nightmare. And I can't totally remember all the sequence of things, but sometimes we went up to Great Ormond Street, sometimes to Guys, sometimes to Thomas's I think. I think it was more Guys, and it was mainly to do with the epilepsy. But by then there was a lot happening in the world of cerebral palsy where people were being operated to release tendons to see if they could walk and things like that. And I think Andrew was being looked at as a possibility for that because of the motivation to walk, but now becoming the physical limitation on being able to. So we had good back up there. Andrew was assessed by the education system and he was supposed to get speech therapy. I mean they were quite detailed, but speech therapy didn't emerge. And it appears that if a local authority can't get the speech therapy then, erm, they're not obliged to provide it. So it was a very, very difficult time. At this time someone suggested a system of communication using a BBC computer. Now this is the early '80s so computers were still very, very new, and very, very unknown, but his teacher loved technology. Absolutely the technology was all important, the person really wasn't. And the first year, okay we survived. Andrew was getting excellent physio, no speech therapy, and appalling teaching. He was very, it all depends how much you know about the status of cerebral palsy and focus and concentration, but basically, erm, his movement are very choral like, and you would think that his attention span was very, very short. In fact with time we've learnt even when he looks as though he's not paying attention he is taking absolutely everything in. But he doesn't need to keep looking at something to have seen it. He looks at it, seen it, okay he can look at something else. So the teacher was complaining that he was always looking around, and we said, "Well couldn't you put him in a position where actually damage limitation, he's not going to be distracted? Even have a side screen so that he can't be distracted." "Oh no we can't do that he's got to live in the real world." And I'm going, "Okay," and this is five years old, six years old, surely trying to learn how to focus on learning was the be all and end all? He went to, and I'm sure it was Great Ormond Street, to see a speech therapist who actually became a very good friend of ours. And she did an assessment and she said, "You know his level of comprehension is that of an 11 year old. But obviously, he can't express it." 'Cause she'd taken him through all sorts of cards and things. And she wrote a report and the school did not like it at all 'cause as far as they were concerned

he was absolutely incapable, and was uneducable. And he remained for that teacher for another year, which was dynamite. And the people at Guys said, "Why?" And I said, "Well actually I think it's because she likes the computer. And if Andrew moves to another group she loses the computer, and she is very into IT." And they were pretty incensed, but quite powerless. Andrew developed the awful situation that he would have really quite a significant convulsion on the Sunday night, and I was pretty convinced it was because he really was fearful of going to school the next day. And there was one occasion he was going to go to Guys for an appointment on a Monday and I said, "I have to say that's if we can get him here because if he has a convulsion on the Sunday night we may not be able to." And they said, "Hmm, why do you think he has it on the Sunday night?" And I explained the link with school and they said, "Well do us a favour, on Sunday tell him very clearly he's not going to school on Monday and that he's coming to Guys." And sure enough we had no convulsion. And Guys and I really developed quite a good rapport. I remember on one occasion they said, "Well why should we gain say you because you've been proven right on everything you've said all along." So we had very good back up with them, but what we needed was that type of support at school and we didn't have it. Things ultimately came to a head when the school said they really didn't want him. And we found another school in Bromley, I think it was, called Coney Hill and Nash House. It was run essentially by the Baptists. Erm, so Andrew was transported by taxi every day to Coney Hill. Again, he still had no communication, but our saving grace was there was a wonderful speech therapist, absolutely wonderful. And we're still friends with her. And she had a terrific rapport with Andrew. He was a teenager by this stage, so there was quite a significant time he was still at Valence. And it was during an educational assessment with and Ed Psych that you know they said, "Really you've got to look for somewhere else." [Sighs]. I can hear the sighs coming out of me because it was good and bad, Judy, the speech therapist was absolutely superb. He no longer had good physio. And he had a one to one, and I'm rolling my eyebrows, a one to one, erm, support worker, whose name happened to be Bruce. My husband's name is Bruce. On one occasion we found fingertip bruising at the top of his thighs. And although I was in education and I did a lot of work with special needs the fact that it was fingertip bruising in such a sensitive place really didn't get my full attention. But I went to the GP and I said, "Look this happened, can you help me?" And he said, "Well what help do you want?" I said, "Well I need something to help Andrew relax so that he doesn't go through the ceiling at school." And the doctor looked at me and he said, "That's about the last thing I thought you were going to ask me for. I thought you were going to ask me to do something about the abuse." And I said, "Well this is our second school and if I ask you to do something about the abuse I believe they will close rank and then where will we be 'cause Andrew will have nowhere. And at least communication with others in a social context is of some value." And the doctor said, "Well who do you think has done it?" So I said, "Well the person Andrew has named to us is Bruce." So he looked at me, and I said, "Yes I know it's my husband's name, but I actually think it's somebody at school 'cause I don't know, but I will try and probe a little bit further." So we contacted the speech therapist and I said, "This this happened Judy." Because obviously, she wouldn't be aware of the bruising. "Could you talk to Andrew about it without my say anything else? And could you come back to me on it?" And she said, "Chris, it's actually very serious, it's Bruce." I said, "Okay. My husband is Bruce." She said, "Oh no, not your husband, it's his keyworker." And Andrew was going through the ceiling at school every time this keyworker came into the room or came anywhere near him. And what Andrew was doing was saying, "Help me, I need help. I need protection from this man. I do not want him anywhere near me." But nobody could understand it. Now that had all happened about the November. Andrew was prescribed by the GP, er, Baclofen, which he's still on, which is a muscle relaxant. And to a certain extent it helped a little bit with the body tone. And potentially helped Andrew relax a bit. But he got excluded so many times for having been screaming, which by this time we knew what it was all about. And February half term came and he went back to school and Andrew seemed a lot more relaxed. And the speech therapist contacted me and said, "Chris, have you noticed a change in Andrew?" I said, "Yeah quite a significant one." She said, "Well you do know Bruce has left?" Nobody had told us. The speech therapist was the one person who thought, hey, this is significant, I need to communicate it. But I think the school were afraid to 'cause they would ultimately be admitting liability for the abuse Andrew had experienced. So we heaved a sigh of relief. And he had a wonderful teacher, absolutely wonderful, who really brought out the best of him. And between Judy and the wonderful teacher things were going really, really well. Judy introduced him to a communication aide called a Liberator. She had tried him on a head pointer. We'd had the head pointer at

home and Andrew put it down the toilet. So I told Judy what he'd done and we all just laughed and said, "This is Andrew saying, hey no, I'm doing this under my own terms, I'm not using switches, I'm not using a head pointer. I will use my hands." Now bear in mind his hands were really not under control at all. The left hand is virtually useless anyway. But he was adamant he was going to hit the keyboard, absolutely adamant there was no other way. Judy was brilliant, she spent hours programming the communication aide to play songs so that he would have to hit particular keys to actually produce the music. Oh talk about motivation, he was so highly motivated. Erm, but along a line somewhere I think his teacher must have moved, and they brought in a woman who was a New Zealander. And you can guess there's another saga coming up. By this time there was a school counsellor, so Andrew had had a very good teacher, a good speech therapist, and a school counsellor, all of whom were totally in Andrew's ball camp, understood him extremely well and got the best out of him. This new teacher, obviously, decided she knew best. Fortunately she made a huge error and in sending emails. At this stage we must have been in the early '90s, so sending emails was far more regular. She copied the speech therapist into some emails where she was complaining about the speech therapists preferential treatment of Andrew to the Head. But fortunately, at least the speech therapist knew the game that was going on. And she contacted me and said, "Chris, I'm going to have to back off Andrew 'cause at this stage my job is going to be heavily on the line from this woman." This woman made Andrew's life hell. Absolutely hell. The erm, the counsellor contacted and said, "Look, I'm really worried about the woman. I think she is quite psychotic, and she is taking out all neuroses on Andrew." She said, "It is very, very clear that I can see them. And you need to be really aware and supportive of Andrew at home because he is going through hell at school." This time we had no option but to raise it with the school. And of course we got the definite reaction, "Oh no, no, no, no there's nothing wrong," blah, blah, blah, blah. Andrew had a very, very bad incident where, erm, we were eating out in a café one day and a sausage got stuck in his windpipe, but it was actually at the time when he was extremely anxious, so his whole breathing pattern was totally out the window. And to quote somebody who actually saw what happened, she said, "Oh, I never thought I'd see you again, I thought you'd popped your clogs." So it was that bad, but fortunately somebody pressed very hard on the diaphragm and dislodged it. But it was at the time when he was under great, great stress. Going back to school in September we were really scared. And then Judy, again, the speech therapist rang us up, or it might have been Jill Brierley. No it was the counsellor rang us up and said, "Erm, noticed any change in Andrew?" And we said, "Yes he's a lot calmer, more relaxed." She said, "Not surprisingly that woman hasn't come back," she said, "And everybody is heaving a sigh of relief." She said, "This school owes you an apology." Needless to say we didn't get one. And in fact the anti was upped and upped and upped. And Andrew became a weekly boarder, Monday to Friday. By this time he'd got a communication aide, so he could communicate. By the end of the year they definitely, he was 18 and they definitely didn't want him any longer. So really he was--, he left school with nothing ahead of him because his education had really been badly, badly let down. Looking back I wish I'd done a lot of education at home, but hindsight is a wonderful thing. And I suppose that's the first time we came into touch with anybody from Social Services and Kingston because by then we had actually moved here. Well to New Malden. And suddenly, I think the school must have communicated to, erm, the borough that there was this young man leaving school and they needed to pick up the pieces. We didn't know that they'd made any communication at all, they hadn't told us. We went away for the summer, we discussed with Andrew, "Okay Andrew, what do you want us to do?" He'd had two very good carers at Nash House, one of whom we're still in touch with, and he said, "Ring them up and ask them if they will come and look after me." Now bear in mind we got no money, nothing. We came back from holiday and I had a surprise phone call from a brilliant, brilliant social worker called Kath Turner, who worked for RBK. Now as soon as the social worker contacted me my hackles were up. I didn't want social work involved, I wanted a private life thank you very much, I wanted to get on with things. Kath came round and she was part of the Welsh Mafia, and she and I both had links with Llanelli, which is very near where I was born. And so we started talking about Llanelli. And I suppose she dissolved all the tension completely. She was brilliant, she said, "Look there will be a care, it won't happen immediately, but you will get funding to help with the care for Andrew. So there will be light at the end of the tunnel. So it must feel awful right now, and I'm really sorry I can't say it will happen immediately, but." The following day she rang up and she said, "I don't believe it, but I've got you funding." So she was brilliant. She said, "But actually I think what we need to do is assess him for the government funding as

well called Independent Living Fund.” So she said, “Please will you write a day in the life of Andrew?” And she said, “And make it as bleak as you can. Don’t cover over any of it, this is your worst case scenario for a day.” So I wrote it, and sure enough he got Independent Living Fund. To get Independent Living Fund at Andrew’s stage you had to have funding from the local authority. There had been a slightly earlier stage, and there were one or two people in Kingston who hit it at the earlier stage, who got 100 percent ILF funding, the national one. To make things really complicated, Kingston in their wisdom decided to call their scheme ILS. So you had ILF and ILS, two different pots of money. Two different assessments going on. You had to have this to be able to have this. You also had to be on Income Support. We had no idea Andrew would be eligible for Income Support. You know we assumed everything would be means tested on us. And Kath was actually absolutely brilliant in saying, “No he's got rights of his own. He's a young man and under normal circumstances what would he be doing?” And I said, “Well he'd be at university.” She said, “Precisely, he'd be leading a totally independent life, and he has a right to that.” So really it was Kath Turner who gave us that. And Kath was absolutely wonderful. I can't remember when she changed from Kingston to being an assessor for ILF. And low and behold she became our assessor for ILF. Now Kath could also be quite fearsome when she wanted to be, and erm, as an assessor for ILF she was rigorous at, you know knowing exactly how things were being spent. But she also was the one who really said, “No this money is for Andrew to use as he chooses.” At that time it was obvious Andrew needed consistency, he couldn’t take variation. He's never been diagnosed as autistic, but there's an element through my own work in education that I would say there's an element of fixation in Andrew. And it goes back to his childhood when he couldn’t speak. He would fixate on something so that he didn’t go mad. Now because my husband’s a minister and we went to church, he would learn hymns, he would learn bible passages. We didn’t know this was all going on in his head. Occasionally he'd come up with something, once he could communicate. And we’d say, “But those were the silent years.” Having left school, now suddenly we had this pot of money, one of the carers he'd had at Nash House recommended a person who worked at the Queen Elizabeth Foundation, and Hazel came into our life as his first carer. And she was with us until ten years ago. So she was with us for nearly ten years. And in a way her family and our family got very intertwined, so when her daughter died at 21, you know it was pretty catastrophic. And we are still very much in touch. But Andrew needed that consistency and continuity of somebody knowing him, especially with the communication needs. Andrew said to her one day, “You know it was really bad at school, they used to take my communication aide from me.” And so we began to get a glimpse of just how bad things during his residential years had been. I digress slightly, but Andrew has a very high pain threshold and he'd broken his wrist once, and it was in plaster, it was during his time when he was residential. And one morning they woke up to find the whole plaster cast intact on his bed. The bones on his wrist had slipped. He was in agony with the plaster cast. So what else do you do? You remove it don’t you? Okay, how do you remove it? He couldn’t have possibly done it without considerable pain and effort. But that's the degree of determination in Andrew. And nobody had been listening to him that he'd got a pain, and that was his way of showing him. So you can still see the slipped bones, and as the consultant said, “Do you want me to do anything?” It happened to be on his left hand, which he doesn’t use. I said, “No, if it had been his right hand I would have wanted you to.” Erm, so yes we've got up to the ILF. ILF was going to close so there had to be a handover meeting with Kingston. At this stage I will definitely not mention names. We had had a preliminary meeting with Kath, where Kath had been her normal forceful self, dotting her I’s, crossing her T’s with me. Fine that's what I expected. And the social worker who didn’t know Kath, came in on it and, obviously, had not got a clue. And now I thought Kath had been in any way fierce with me, she made mincemeat of this social worker. Absolute mincemeat. But I was very aware that the continuity plan between ILF and Kingston was in the social worker’s hands. And that was bad, bad, bad. Erm, we had that social worker, I think maybe for another visit, but not much longer. And she knew she was totally out of her depth. She suggested I needed a carer’s assessment and a carer’s allowance, and I said, “What for?” “Well so that you can buy in help, so that you can have a night off looking after Andrew.” So I looked at her and I said, “Okay, I see. So you'd like me to set myself up as an employer with a separate payroll for anybody I employ to do what Andrew’s PAs do for him. So I have to do two payrolls instead of one.” “Oh no you don’t have to do that.” I said, “Well if I'm paying people legally that's what you're asking me to do.” “Oh no, no, no, no. Totally unnecessary.” I said, “Well I think possibly you need to go back to the office and discuss this with somebody.” I said, “And incidentally, where is the money coming from for

my carer's allowance?" "Oh directly out of Andrew's budget." So I said, "Whoa. Andrew needs every penny he gets. He doesn't need to lose it because I'm being given money. And I don't need it. So forget any carers assessment." And I've still got a copy of the form where I've scrawled all over it, never ever come near me with another carers assessment. So I think I'm about the one thorn in the flesh of ASC who does not have a carer's assessment because I am totally resistant after that bad experience. Erm, Andrew battles Kingston funding? Hmm, yeah just slightly. DRE's, Andrew must have one of the highest level of in needs for equipment in the borough because he has no mobility, so he has to have a vehicle. He has to have a communication aide, which initially cost £7000.00, which has a life expectancy of five years. On top of the £7000.00 there is a £3000.00 insurance service charge, so it's £10,000.00 for five years. £2000.00 a year. Based on benefits £2000.00 a year is a hell of a lot to have to save. If you're a wheelchair user and you have a mobility allowance any car you buy has to be adapted for a ramp. Maybe the floor lowered. So a very basic rudimentary car like a Kangoo we had, instead of costing six or 7000, which in those days it did, suddenly the price goes up to 12, 13000 for the adaptations. So therefore you're talking about a far more expensive car than the actual car is. So we took out a car loan for the car 'cause I thought somewhere I've got to be able to show that Andrew is paying this money otherwise they're going to say you don't need that money for DRE's. And somebody in the finance office, 'cause in those days the finance was handled by finance not social care, actually said to me, "Well if you will buy such a luxury car." So I said, "Excuse me, you call a Renault Kangoo a luxury car. Have you any idea how expensive a conversion of a car for a wheelchair user is for them to be able to get into it?" So very grudgingly she accepted the amount we were paying out in the car loan. And I thought, I'm not going through this hassle again, I will start using Motability 'cause then they're not going to argue come what may 'cause they'll know it's out of their hands.

Q2: Sorry, can I ask quickly, what does DRE stand for?

A: Pardon:

Q2: What does DRE stand for?

A: Disability Related Expenditure.

Q2: Okay. Thanks.

A: So the expenditure that the local authority takes into consideration when they look at the money you have. 'Cause they've got full access to all your business accounts, they know everything about you. And it's an allowance over and above what the government says you need to live on for being disabled. And it's directly for things like equipment. But you can imagine somebody querying that from a position of total ignorance. Kath was still our social worker at that time and she said, "I hope you've made a formal complaint about it." I said, "Well actually I haven't, but it's irked me." And actually it irked me so much that I still use it as an example. Erm, [pause].

Q2: At the time when you were first getting assessed by Kingston Council what other recommendations were they making in terms of Andrew's care or for adaptations to the home?

A: [Laughs]. That's another matter. Okay adaptations for the home. We'd bought this. Kath knew about it and she said, "You need to contact Kingston to do conversions." So I contacted the department and immediately the woman said, "Oh yes you'd like our advice so that you can privately make the alterations." So I said, "Oh well, if that's what you say, yes." So I told Kath and she said, [Smacks hand], well I won't quote her directly. She said, "The stuff and nonsense, these are conversions for Andrew, they're not for you. He can't afford any conversions." Surprise, surprise I got a phone call the next day from the same people saying, "We're coming round to make an assessment for the alterations that we will undertake to do." So again, we were so fortunate to have this woman 'cause she was there fighting our corner all the way. And I was a novice, you know I wouldn't have known anything. And the DRE is an on going battle. Well they were when it was under finance. And I always remember one occasion 'cause I'd

dotted my I's and crossed my T's, I'd done an accurate assessment of how much a week Andrew needed say both for the car and for the communication aide. And the communication aide came to £40.00, I think a week, it might be a month, I might have got it wrong. But it came back £4.00. A significant difference there being allowed. And bearing in mind Kingston at this stage, I think were taking 50 percent of your disposable income, so it was actually quite significant that if they took too much he wouldn't have enough money. So I rang up and I said, "You may have made an error, you may have left a nought off because I know I put in 40 and it's come back four." "Oh no we thought that was far more reasonable." So by the time they'd scraped me off the ceiling I said, "It might be reasonable, but actually the 40 is what it actually costs. And so you can't suddenly say, well we're willing to pay four." This social worker who took over from Kath, it was at a time where finance for some reason known to finance or RBK, lots of rolling of eyes on my part, decided in their wisdom that the best people to handle the finance part was social workers. We had a social worker who had no financial nous whatsoever. And she said, "Communication aide, that's ridiculous that should come under health anyway. And why on earth are you paying all that money?" "Cause actually that's what it costs. And actually we're over a barrel because the language he uses is only available in this particular piece of hardware." So she said, "Rubbish, you can just get one for £1000.00." And I'm going, "Hmm, okay. We'd be interested to see how you come up with that." Surprise, surprise our next assessment we had a totally different social worker who had an accountancy background. And I can't help but think somewhere along the lines they had decided that possibly they needed somebody slightly more competent when it came to talking about finances if you're going to talk to a mathematician. And I've got a feeling that the person knew that they were out of their depth. I'm terrified of her resurrecting herself because I'll put a complaint in before she even steps in this house. So I'm hoping she'll never resurrect herself because she's causing a lot of trouble locally. We ticked over with this social worker relatively well. He would say, "Do you mind giving me those figures? You know save me doing them." So I was providing him with half his job, which was fine. But he trusted my figures and he was an accountant, and he knew I wasn't cooking the books. And that worked on relatively well, but he was a locum. Two years ago I recall saying to him, "Look our current carer has been with us, at that time eight years, I really need to give him a pay rise. I'm already paying over the odds, but we compensate by doing a hell of a lot of the care ourselves. So can I give him a pay rise?" "Yeah no problem." That was two years ago. A year ago he came and he said, "Oh look, this is my last visit because I'm leaving. Oh and you're paying over the odds, you know that could cause a problem." So I said, "Well I'll fight that battle if it causes a problem." Because under the Carer Act, obviously you'll be aware it's needs based, and continuity for Andrew is absolutely paramount. And certainly when it comes to any care plan, if I ever see one in writing, erm, 'cause I have not seen one since Kath left. I have got one care plan that says so many hours at so much an hour, period. And that is the whole care plan. If you can imagine how embarrassing PIP finding us and putting us through an assessment, wanting a care plan and saying, "Well I'll show you the only one I've got." And I don't know how there aren't big problems locally on the quality of their care plans, and their whole quality of their assessments and interviews. But that's partially because I've been on a few, erm, discussions at Inclusion London, so I've most probably got a little bit more knowledge than many people in the borough. Which I shared, but nobody really wanted to know. And I will share fresh knowledge I've got. But again it is highly unlikely people will just get picked off on their own. And there's no corporateness for people to gain from other people's experience, which is unfortunate. It's accidental if there's any networking that takes place. There was one case, I was in KCIL one day, and obviously, I know Lisa and Robert very, very well, and I know most of the people, and they know me. And 'cause you may or may not know that I've been the front piece for taking on Kingston twice, two years running. Unsuccessfully this year, but successfully last year. And on one occasion somebody had gone in very upset after an assessment and I happened to just walk into the office and Lisa laughed and said, "Oh Chris, you're just the person we need." So I ended up working really in an advocacy type role for that person. And I'd been working in an advocacy type role for somebody else. But it's been accidental that they and I have linked up. And it's difficult. Anyway that's really about brought you to full circle, except Theresa May has called an election. ILF finished a year last July. The funding from ILF was supposed to finish a year this April. A government minister got cornered on record on the radio by some activists from ex-ILF users about the way this money had not been ring fenced going into local authorities. We've managed to effectively get it ring fenced, erm, just because I'd been so up front. They were a bit afraid of losing sight of that money 'cause they knew I'd be on their back. And the government

minister said, "Oh it's guaranteed until 2020." Which actually is, was the prospective date for the next election. Everything's gone very, very quiet, but all those election promises have now gone out the window. And so for example, when there was the big trouble with Ian Duncan Smith and David Cameron, and George Osborne doing a U-turn, and Ian Duncan Smith really being very angry, erm, Stephen Chalke came in and said, "Ah yes there'll be no more changes during this government." We've lost three years of this government. Whatever happens this will be a new government. And yesterday we can already see the way it's going, and if she thinks that is giving disabled people and elderly an advantage and she's there for them, she's got another thing coming.

Q: I know that you've talked a lot about--,

A: Sorry, could you--,

Q: Sorry. I know you've talked a lot about Andrew, yeah. Can you talk to me, you know talk to us through, erm, say what a typical day for caring for Andrew is like?

A: God. [Laughs]. Ooh, if we're going to start on that ask your question again.

Q: Can you talk me through a typical day of caring for Andrew?

A: Caring for Andrew is a totally uphill battle. You are fighting officialdom, for example, you might be called in--, when Andrew was about four or five we lived in Sevenoaks and he was called for an assessment for attendance allowance. To a meeting in Tunbridge Wells. And when we got there it was a two storey prefabricated building with the assessment being upstairs. So I had no option but to take Andrew out of his pushchair, carrying him up the stairs and do in. and the doctor just looked at him and said, "My god," he said, "How the hell did you get up here?" I said, "Well I took him out of his pushchair and carried him up here." He said, "You are never ever to accept an assessment other than at your home." He said, "I'm writing all over these forms right now, you are not to be called up to any office." Because one of the games they play, even with PIP, they might ask you to go the other side of London to see if you can get there. And it's all part of the process of assessment, they can do this so they don't need help. So it's a never ending battle and fighting, and it's pretty awful. Within education the constant educational reviews, and they can be really stacked against the parent and child. I suppose I've been very fortunate, I've had a lot of inside information when it came to the world of education because I did a lot of work along those lines from the school's perspective. Now it actually helped me, I hope, temper the practice in my school so that in actual fact it wasn't stacked against the parents, but was more supportive. And if anything the professionals had a harder time. But that was by nature of who I was. With Andrew, with the lack of communication he and I have a terrific understanding between us. It is very, very draining. And trying to be on his wavelength the whole time is really difficult. He has a very clever way of putting words together, but sometimes if you're not on the right wavelength you don't totally understand and there can be fireworks. So you've got to be 100 percent alert. If you go to the GP the GP will usually say, "Well what do you think is wrong?" And the responsibility and the onus is really quite considerable and great. Erm, but I've got every sympathy with them because the level of communication is really, really difficult, and I'll say, "Well one of the reasons I've come here is to ensure I'm not missing something, and I really need you to look at it." Once a person is 18 there is no on going medical specialist advice, especially for something like cerebral palsy. There might be for some other conditions, but we've had no professional overseeing Andrew. Erm, and in fairness to the social worker who took over from Kath, she was the first person who said you can have a wheelchair assessment. So in fairness some good came out of it. And the wheelchair people have been absolutely brilliant. But now they are saying they're really worried 'cause Andrew's head is down on his chest, and it is likely to get further down so it's going to cause more breathing and eating difficulties. And we've been watching it visibly deteriorate, even since they pointed it out. But about a year ago I asked the GP for a referral for physio, and the physio wrote back saying because it is not a skeletal problem we cannot give physio. If you can explain to me how spondylitis, head coming down to your chest, foot going over so the bone joints are being really quite badly damaged is not skeletal in any way, I would be very grateful. But if

Andrew had had on going physio I think a lot of these problems would have been pre-empted. The hamstrings behind his legs are so tense and tight he really can't straighten his legs. So even at night time they have to be bent. It's an on going battle. Erm, he's recently complained of toothache, so we've had to have a new referral back to Guys Hospital. And we're still waiting for that to happen. Everything is just one on going fight. Local authority? Yes well, erm, I'm very, very grateful to them in one respect. If they had not been so far thinking 20 years ago Andrew would never have got such good help. Had we been coming into the system now, no it would not have been as comprehensive and as well structured. And the huge danger now is where are we going? A landslide victory it will be disastrous for social care. She is claiming she's putting more money in, the money is going to be coming from the claimants. She is not ring fencing it. As she herself has said, it will be up to the local councils as to how they spend it. And I can promise you our current local council will not prioritise social care for that funding, they will have better uses for it. So you have to be very shrewd, you have to be very astute. Steve Taylor, who is director of ASC said, "But at least you're there, at least you're concerned, at least you're active." And I said, "Yeah, but it's at great expense to my own physical health." 'Cause my blood pressure is really dangerous. At the moment it's as well controlled. I am aware that my family history is in the field of aneurysms and strokes, and nothing else. I can see the time bomb waiting for me. I actually have a heart monitor in because I have had some very funny turns and they're trying to find the root cause of it. But at the moment they are not linking it with the heart, but they did find some blip recently. But that's really the physiological strain. If somebody is in screaming agony at night and you are getting up to deal with it the following day you are good for nothing. And the fact that you've got care coming in, which takes the pressure off you is the life saver. The government is now saying people can have a year off to care. Notice they are not saying a year off with pay. Even the year off to care will cause devastating implications for employers. And financially will be bringing real hardship for the person doing the carer. Erm, my husband and I work pretty well together on the physical caring. Erm, sometimes it's his turn, sometimes it's my turn. It's more often my husbands turn at night. Andrew had a few convulsions a year last February. We eventually got to see somebody for convulsions who informed me Andrew had never ever had epilepsy, and that they really weren't convulsions. So I said, "Oh interesting that's why he was on Epilim and under Guys and Great Ormond Street for ten years of his life. And you've got the notes in front of you have you?" So when the note came through I had started off the whole meeting saying what on the day of the convulsions the hospital doctors identified an infection, so what infection was it? And he looked startled and he said, "What do you mean?" I said, "Well they found an infection in the blood, did that cause the convulsions?" 'Cause he was trying to pooh pooh that he'd ever had convulsions. The same, well I don't know if it's the same doctor, but they've told somebody who has such serious convulsions they've even broken a bone in their back when they've been having a convulsion that they were having pseudo convulsions. And you go, "Hey, whoa, this is just cloud cuckoo land." So when Andrew had another convulsion in August no way am I going back to that man. So I'll now have to fight if I want anything done about it for a referral to a totally different hospital. That's the type of strain. Erm, last week I had an appointment at the hospital for Andrew on the Monday, an appointment at the hospital on the Tuesday for Andrew. You know that type of constant thing. Erm, there's no let up, absolutely no let up. My husband and I, since Andrew has been born, and apart from the week where he was away Monday to Friday at school, we had two nights in Paris, three nights in Minneapolis when we went for a relatives funeral, and the first carer did both care patches. Erm, we've got a wonderful carer at the moment, who comes with us on holidays. But he's setting up a job interview for possibly in York, even as I speak now. So that is likely to end. Andrew's current carer, his father died just before Easter, he has a partner who lives in Amsterdam with a little girl, you can see the way my thinking is going. And we are aware that trying to get the maximum stability for Andrew is our top priority. Fighting Kingston is a real pain in the backside, which we could do without. But I suspect soon, very soon I'll be back into that fighting Kingston because somebody is going to ring up saying I need an assessment, and we'll take it from there.

Q: What do you hope you'll see happen in the future to continue supporting people with conditions such as Andrew's to better manage the activities of daily living?

A: You want my hopes and dreams or reality?

Q: Both.

A: Reality is going back to the dark ages, and there will be very little help. A disabled person will be incarcerated in their own home 'cause they will not be able to afford to go out. 'Cause the expectation is that they do not have the right to expect a life on top of being alive. That is very clear in this current manifesto. And those are the implications. My hopes and dreams? Good job you're talking to me today and not yesterday. And this is in the context of the manifesto having been published yesterday because actually I really wondered upon our death what on earth stability we can leave for Andrew's life? We've attempted to set it up that he will have this home that he will be able to live in. This now necessitates that my husband and I living healthy lives until our demise, so we do not need care that we do not have to drain our resources, which will leave Andrew destitute. So the hopes and dreams are that we will set it up that Andrew will be able to continue here provided he gets the financial support he needs. We have a solicitor friend who 38 years after the day is still urging me to see if we can get any legal address. Partially based on the grounds that times have changed and circumstances have changed, and what we believed to be a reality when Andrew was born is no longer the reality. And it is very, very serious. When I fight I do not fight just for Andrew, I fight on behalf of everybody. And I am about ready to really, really stir things up in Kingston. But it will be at my expense. And I'm disheartened because you know I know the strain it puts on my body and I don't know how much my body can take the strain. The one thing I haven't mentioned is, erm, for the past 25 years I've got really quite serious back trouble, and so I have to be very, very careful about my back. And handling Andrew is another matter. incidentally the new care worker, erm, social care worker seeing that we had a hoist, we don't actually use it, said, "Oh well, of course you've got to have two people to use the hoist." So all I can say is, so therefore we need two PAs in the middle of the night to get Andrew up and about to go to the toilet. And don't talk to me about incontinence pads 'cause McDonald's has already won a legal case on the loss of dignity and not meeting their needs, and boy oh boy, I'll be there. So I suppose I'm very fortunate I know a lot of what's going on, and I know what should be going on. But there's a lot of that you'll need to edit out.

Q2: Mm. [inaudible 1:39:09]. Thank you so much Chris.

A: Okey doke.

Q: Thank you for your time.

[END OF RECORDING – 1:39:17]