



Speaking for Ourselves: *An Oral History of People With Cerebral Palsy*

Kay Bath
Interviewed by Jill Mahler

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Interview Summary Sheet

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Track 1 [Tape 1 Side A]

Interview with Kay Bath 12 April. Kay it's very nice to meet you at long last. We are here to talk about your experiences of being a person with a disability. You can talk as you wish or if you want me to ask you questions I will but we'll just take it as it comes.

OK, that's fine. Maybe you could start off with one or two questions and then...

Have you always lived in Bristol?

Yes, apart from two years when I was in Coventry where I went to a special further education college.

So which one was that?

Hereward College.

Oh yes.

But that was many years ago when it had just opened.

Well, we're going to go back even further [door opens with a squeak] [laughter].

Yes, if it would help you maybe we'll start at the beginning, when and where you were born and how it was.

I was born here at the then BMH [Bristol Maternity Hospital] and that was here in Bristol. My mother had a very difficult and traumatic birth and I think if it happened today she would be offered a caesarean but it was a forceps delivery and they got me out safely but obviously, you know, the lack of oxygen...

Mmm.

Yeah 'cos she was awfully torn as well, so she suffered.

So did you both remain in hospital for longer than usual or you came out?

No, they [both talking together] I mean because they thought I was fairly fine but Mum and me, you know... They sent Mum home, you know, just very sore and having to cope with a new baby.

Mmm yes. So did you have any problems initially with sucking or?

No.

No.

No.

So you seem fine, when did your mother or parents feel there could be something the matter?

I suppose when I was coming up to about one, maybe a bit longer... When other friends of hers that had babies at the same time and I wasn't obviously behaving in quite the way that they were and she pestered her doctor and finally got a referral to a consultant. I don't think it was at the initial one... and she kept going back saying, 'There's something wrong with my baby.' But I know she told me that one day she was in this room and he came in with his full pack of student doctors and they gave her the diagnosis that I had cerebral palsy. And he said to the students, 'You should learn a valuable lesson from this; always listen to the mother because the mother is always right. They knew their baby far better than you do.' So hopefully some of those doctors took it on board. [Laughs.]

Yes. So was she given any explanation what cp was or did she know what it was or?

No.

No.

No.

So she came away thinking, 'What on earth?'

Yeah.

'What hope?'

Yeah but she didn't give up fighting because here in Bristol in [whispers inaudibly] it might have been in 1954, '55, Claremont School opened [both talking together].

Oh yes.

And my mother managed to get me in there when I was three and a half. And she must have had some help because I remember her telling me that other mothers with babies with disabilities were saying, 'However did you get your daughter into there?' Because everybody was trying to get their child into Claremont.

Why was this? Why did they want Claremont?

I think because it was education and also it was therapy. Therapy played a huge part in the school because all the classrooms were downstairs and all the physio and treatment rooms were upstairs, the whole of that floor. And the headmistress at the time was Miss Ram [ph], now she was a very good head.

Good.

Yeah.

So you went to school when you were three and a half. I'm not sure about Claremont; is it quite a small school?

Yes it's an old house, really old-fashioned. Quite a big house obviously belonged to somebody that had money at one point. But yes, it was quite a small school. There were one, two, three, four, about five classrooms.

So every child had a physical disability?

Yeah and the majority of them were cerebral palsy.

And did some have learning disabilities too?

Not that I remember.

No. So educationally did it follow the general curriculum?

No. [Laughs.] There wasn't a national curriculum then. No and I think they adapted the learning practices for those that were maybe more physically disabled than those that weren't. Yeah.

So you continued there to what age?

'Til I was about eight 'cos I wasn't allowed to walk. I wanted to try and walk and obviously that's what my parents were aiming for. But the physios at the school, I think I tried to get up on my feet when I was five and walking on tippy toe and that was a 'no no', so it was back to crawling. And then I think just after my seventh birthday – we lived in quite an old house – and I was in the front room and I crawled out to the hallway and obviously didn't have any sense 'cos I used a flat wall to pull myself up on and I then sort of walked into the kitchen and said, 'Look Mum.' And that was it; they didn't keep me down after that.

Good.

But they used to put you in plaster casts about every six months to try to get your heels down.

You weren't offered surgery?

No.

Yes.

No.

So did you hate this plaster cast thing or were you philosophical? [Laughs.]

No, I mean I hated them 'cos well they were just so unwieldy [both talking together] and you know, what child wants to go round with sort of two plaster of paris boots all the time? But that was something you got through. And then next door to Claremont there was an infant and junior school and the grounds sort of sloped down to a little brick wall, which was about three foot and then you were in the Henry [ph] School playground. And I don't know who came up with the idea but it was decided that three of us would go to the junior school for half a day. [Laughs.] So they used to take us over in the morning and we had to come back for dinner and also to have the rest on the camp bed 'cos every child had to go on their camp bed. And that carried on for quite a few months and we obviously were coping – the three of us that went – and we were the first children in Bristol to be integrated into mainstream education and we finally went full-time, which was great fun. Yeah, that was brilliant. [Feedback noise from microphone.] [Break in recording.]

OK?

Right.

Yeah. I'll try and survive both ears [laughter] OK.

I progressed through the junior school and obviously when I was approaching 11 it was, 'Well what do we do 'er next?' And we looked around at various options but it was decided by the 'powers to be' that I would go to Monks Park Comprehensive, which was over in Horefield [ph] and I lived in Fishponds. So the education authority council agreed to pay a taxi to take me to and from school, which straight away sets you off from the others. And also friends that I made over there, when I went home at night they weren't there because I didn't live locally. The first two years was spent at the lower school, which was why it was chosen because it was a single storey building. But they didn't look very much into the future because years three and four we sort of crossed the road to go to the main building and it was a three-storey building. So I now had to cope with two flights of stairs and it's not just like going up, you know, at the beginning of the day and coming down lunchtime, you were going up and down all day because obviously in a secondary school you move and not the teacher. But I was physically then able to cope with help from my friends, you know. They'd carry my bag. It was tiring. It was a struggle but when you're that age you didn't really know of any other option. And it's, you know, 'Oh isn't it good and she's, you know, in school – mainstream school – she's coping.' Although I was bullied. That went on for quite a while and I decided to fight back.

Good. How did you cope with it?

I was very upset with the bullying at the time. I think it was just 'cos of me and the way I walked at the time.

Were they all contemporaries or older people?

No, they were my classmates basically. It was one girl really [inaud] one girl and there were the others that would stand around. I mean it wasn't physical; it was all mental abuse really.

Verbal, yes.

And my mother rang up one day and said, 'Look, you know, we have to do something about this bullying and Kay's really unhappy and I'm not happy with the way it's going on.' And headmaster said, 'Well, it's all right, don't worry about it. Kay's dealt with it herself this morning.' And I think I finally fought back and yelled things at her and shouted at her and told her a few home truths and that was the end of the matter.

Good for you.

Yeah.

Right.

But I'm like that, I'll take so much and then... [Both talking together.]

That's great

So I went through that fairly normal life really, apart from not having my school friends near me and being able to do things after school. I went to sort of school discos and stuff – Dad would ship me over – but it was quite lonely.

Yes. Did you travel over by special taxi or with a big bus emblazoned?

No, it was an ordinary taxi, yeah [both talking together].

Good

'Cos it was only me going there. Well, it was fairly near to Claremont, so we used to drop off two or three at Claremont, then he'd take me to school and then he'd pick me up and do it in reverse way.

So I guess in a way a sort of fairly normal life until I was 16, I'd just taken my mocks and I became ill with glandular fever.

Oh dear.

And I was extremely ill, I was in the BRI [Bristol Royal Infirmary] for three weeks with it and my parents were called in on about two occasions because they actually thought that I was going to die because my temperature, they couldn't get it down. And so I remember laying there with fans everywhere and iced water and... But I came through it but not quite myself. I was off school from the end of January 'til the following September, in which time all my friends had taken their O'levels and most of them had left school. So I went back in the September not knowing anybody and realising that I could no longer cope with the stairs at all. I was a lot weaker than I was, so it was, 'Well what do we do with her now?' So I used to sit in the sixth form block library doing work that they gave me but I wasn't really studying for anything. I'd missed my O'levels, I couldn't really get into the A'levels, so I was a problem yet again. They had a very good deputy head and she was the one who actually found out about Hereward College for us and I went up and had an interview and it had only been opened six months and they agreed to take me at the Easter. And I went up there and I have to say it was such a relief.

Yes, I've heard that from someone else too.

Yeah, such a relief. I could be me. I didn't have to give 200 per cent to keep up with the others that were giving 100. You know, if I was tired it didn't matter. And obviously the whole college was adapted, it was all with ramps or the lift and everybody took into account your disability. I had a brilliant time up there.

Good.

Yeah, really good.

Good. So were you on track to get qualifications or was it vocational?

Well, I did turn out to be vocational in the end; I did a certificate in office studies up there for 18 months. But a few landmarks; I got my first Invacar up there.

Oh good. Freedom.

Freedom.

Oh yes.

But it was a lovely place in the community 'cos we were, you know, in a residential area and everybody's local, the pub, was exactly opposite our college and of course being adults of a certain age we would go over and partake [both talking together].

Oh good.

But I mean not... the locals and that just accepted us and it was great, it was really good time.

Good.

One of my happiest times.

Good.

Yeah.

So did you do other studies there too like media studies or acting or...?

No.

Really? Secretarial?

Yeah.

So did you decide to pursue that path or were you told you were going to do it?

I think I was probably persuaded, I didn't really know what to do because all of a sudden I was going down one track of O'levels, A'levels and then it just all sort of got blown apart a bit and it was hard picking up the pieces.

So what did you do sorry, I mean to what end did you do this? Had you an aim from the beginning that you were going to be a receptionist or secretary or something?

Yeah, a secretary I think more than a receptionist. Yeah but when I came back to Bristol I actually went to work for National Westminster Bank in their registrar's department dealing with stocks and shares dividends.

Oh, very interesting.

Yeah.

Was this in Corn [ph] Street? In the main building?

Saint John's Street? We were right opposite the courthouse [phone rings].

Yes.

In Bristol.

So you used the Invacar to get to work?

Well, the first week my dad took me and he got me in there obviously for nine o'clock, which meant leaving home at eight o'clock and he picked me up at five o'clock. So I did this for about three days and I was... I remember on the first day I got in the car I fell asleep. I went home, I didn't eat tea, I went straight up to bed; I slept 'til seven o'clock the next morning, got up, dressed, got in the car, went to work, did a repeat of Monday. And the same again Wednesday and I said, 'I can't do this, so I'm gonna have to leave.' Cos I really couldn't see any way out of it. So I went into my manager's office and in those days when you were registered disabled you had a green card and I was the only disabled employee that they had.

So they weren't fulfilling their quota? [Laughs.]

So and they didn't want to let me go obviously.

No.

So we decided that I would get in at half past nine, which meant I left at nine and missed all the traffic and I left at half four and again missed all the traffic coming home, beat it. So I wasn't being so tired and I had my own special car parking place [both talking together] along with all the other managers' cars.

[Laughter.]

Yes.

An underground car park. But yeah, it worked out well.

Good. Now we have missed out an important part though, how you got that job. Did you do it through the DRO – the disabled resettlement officer – or did you apply direct?

I applied direct.

Good.

Yes.

So there you were ensconced in Nat West, how were the other staff?

They were brilliant.

Good.

I didn't have any problems with any of them. They were all really; there was just no trouble.

Good.

I was just treated as one of the other members of staff.

Yes.

Can I have a break a minute?

[Microphone feedback noise.]

Sorry.

[Break in recording.]

OK.

I was working in the bank and I met my first husband at a special club, funny enough, for disabled people down in Old Market, in Bristol. He was able-bodied and a part-time DJ and he used to go down and help, and if they had a disco he'd do it. And I

met him there and we went out for two years. We'd been going out together for about a year and he suggested going on holiday. [Laughs.] So put it to my dad and he said, 'Yes, I've got absolutely no objection to you going away as long as you get engaged first.' [Laughs.] Which was really funny 'cos what the difference an engagement ring was going to make I really don't know. So we went away. We had the big white wedding up at the local church and then about two years later I had my son.

What's his name?

Kevin.

Kevin.

And he's now 28.

Huh, yes!

And that for me I guess was quite traumatic because nobody at the hospital had any dealings with a disabled mother. I was put in touch with the Spastics Society local social worker who had never dealt with a disabled mother and...

What year was this?

Seventy-seven.

Good heavens.

But that was still the time when disabled people weren't supposed to be having sex let alone having babies [laughter]. And we were looking to get some form of equipment that would help me because although I could walk of a fashion 'cos both legs were affected and my right hand, I couldn't carry a baby in my arms 'cos my balance wasn't brilliant. And I couldn't get down on the floor to change 'im because I could

never get back up, so [inaud] she did an awful lot of research and in the end we just decided that we'd have to use... I bought a Maclaren buggy pram that at that time was all the rage and just put...

[End of Track 1

Track 2 [Tape 1 Side B]

So my husband went out to work, Kevin and I stayed in the lower bit, which had the kitchen and a dining area and it was sort of all open-plan anyway. And it had the bathroom and his bedroom down there because I couldn't really get him upstairs on my own until he was older. So that was hard and I'd lost my Invacar.

Why was this?

Because I couldn't take Kevin in the car with me. So that went back, as my husband worked shifts, so I was either on my own from early morning 'til mid-afternoon or mid-afternoon 'til late at night, so that again was quite a lonely spate. And we then moved to another small two-bedroomed bungalow but this time it was all on the level, so that was a bit easier and I learnt to drive. My first car was a Daf and I thought, 'Well, where do I go?' I didn't think I needed, I didn't even think about adaptations, so I got in the car and I think I went out with my dad just to see if I could manage it really and yes I could.

Was it an automatic?

Yeah.

Yeah.

It was one of those rubber band cars. [Laughs.] And I thought, 'Well where am I going to go, you know, for a driving instruction? Are they going to take on a disabled driver?' I didn't have a clue. So I got the Yellow Pages out and was looking through driving instructors and there was a fella advertised that he would help deaf people and I thought, 'Well that's a good start. If he deals with deaf people perhaps he'll deal with me?' [Laughter.] So I rang him up and he took me on and I eventually took my test and passed first go.

Good.

So then that was brilliant. Yeah, that was freedom again.

Yes.

You could go wherever you wanted.

Did you get motability in those days?

Yeah but I mean they obviously didn't have the purchasing car schemes. [Both talking together.] It was just the allowance.

No. So with this squirming baby how did you manage with dressing him and undressing him?

The social worker... when we were looking for stuff and we went down Mothercare and they had this special – well, it was [an] ordinary one members of the public could buy – but it was a changing unit and it was quite small and square but then it would pull out and it would reveal drawers that you can store stuff in and then it was like a big changing mat on the top. And it was at a brilliant height for me, so that's where everything got done. Yeah, right there.

When I remember with my first baby he squirmed and wormed everywhere I had to hold on to one leg all the time...

Yeah [both talking together].

But babygrows were a godsend I found.

Yeah, you just grab a handful [laughter]. Yeah, they were brilliant.

So there you were in your car, you had your wheels, you were mobile.

Yeah.

So what next? Did anyone suggest the mothers' groups, playgroups?

Well, when I first brought Kevin home you had the midwife come round. I was in there for 10 days because I had a caesarean with him and had the midwife round for a couple of days and she said, 'Oh, tomorrow the health visitor will be round, it's the end of my time now.' And I said, 'Oh right, OK.' And the next morning sometime the doorbell went, well I was actually sat in the lounge and Kevin was in his carrycot sound asleep. So Geoff let her in and she came in and came up and we were chatting and then she said, 'Well, you know, can I see baby?' So I got up and walked across the room and got Kevin, she didn't show it and she told me many years later, she was absolutely horrified.

God.

And she really thought that Kevin was going to end up in care. Nobody had told her that I had a disability, so she was totally unprepared for it and she really thought I wasn't going to manage. But I proved her wrong.

Of course.

[Both talking together.] It wasn't even something I ever thought

No

Of not being able to do. But I've gone through life with that attitude anyway

Good, yes. [Both talking together.]

So yeah. Anyway she arranged, when Kevin was about two and a half, that he go to nursery one or two half days originally and then days a week to integrate with other children and that was brilliant – I mean for him and for me because I had a little break and could do what I wanted to do. And he loved it; it was a lovely nursery not very far from where we were, again in our old house. And the matron, whatever she was, she was a wonderful person and I was just another mum up there, they totally had the right attitude. Yeah and everything went swimmingly and when Kevin was four and a half I had my daughter Katie who is now 24. Again it was another caesarean and the pregnancy was OK. I got very tired especially with having Kevin as well. And with Kevin they decided to do the caesarean at 38 weeks and with Katie they decided to leave it 'til 39 but whatever I did I wasn't to go into labour. [Laughs.] And she was born at the end of January, so it must have been about the middle of January and we had an absolute blizzard of snow, it was thick everywhere. So I started getting these pains and Geoff said, 'Well I can't get you there.' 'Cos like the snow was about three foot, so we had to ring for an ambulance to take me to the BMA and it took hours. And we came out of our road and got on to the main road and I can't remember his name but he was a news presenter on the local HTV station at the time, in all these feet of snow, riding his bicycle. [Laughter.] And the ambulance driver was going, 'Look at that idiot.' [Laughter.] And we were on our way to hospital. But I got in there and stayed there for a couple of hours and then they sent me home again and that went on two or three times, so in the end they finally kept me in and performed the caesarean and I had Katie.

Did you have any fears or any feelings about, 'What if my baby is damaged too and has cerebral palsy?'

I think I did more with Kevin [both talking together] than Katie. I knew it wasn't any point in having something like genetic counselling. So it was just a wait and see but I mean I was worried yeah about how I was going to cope with an ordinary baby. How I'd have coped if he'd been disabled I really don't know.

So before Katie was born had Kevin by that time become fairly self-sufficient and doing things for you... collect... and going to get things [both talking together] or just...?

Yeah and... No, I tried not to say, you know, 'Pick that up.' But when it came to his own toys, well you can pick your own toys up yeah [both talking together].

And how did he welcome Katie?

He was wonderful.

Good.

Katie brought him a present and he came in to see her, 'And she's heard about you and she's brought you this present.' And it was a little model car that he'd wanted. Funny enough a couple of weeks ago we were talking and he said, 'I always remember that car that Katie gave me.' [Laughter.] Really funny. No he wasn't jealous he was really good. He, you know, he'd wait if I had to feed her, change her or anything. But I mean he was four and a half and then she was born end of January and September he was starting school, so... but no, he's like that, he's quite sort of laid back.

Good. And was Katie fairly amenable as a baby or was she quite different from Kevin? [Laughs.]

Well, Kevin did get his odd moment, odd tantrum. I always remember my mum and dad took him out for Sunday lunch, I don't know how old he was, three or three and a half, at a place in Keynsham. And the restaurant was upstairs and Mum and Dad were sat there and Kevin decided to have tantrum, so Dad was going to Mum, 'Do something. Do something with him.' And by now I think Kevin had got under the table. 'Do something with him. Stop it.' And in the end my dad walked out and left my mum to deal with it. [Laughter.] But that was bad.

Before we go on I don't want to stop you in full flow if you want...

No, that's all right [both talking together].

But talking about your parents, I wonder do you have any brothers or sisters?

I have no brothers or sisters.

Aha, so you were unique? [Laughs.]

Yeah.

OK. Did you feel it was a problem not having brothers or sisters?

Not growing up.

No.

No. Although I always wanted an older brother which obviously I was never going to get but I really wanted an older brother. And well, around the time when Katie was born my mother was diagnosed with breast cancer but she successfully had the lump removed and a course of radiation and she overcame it. But it was at times, I think that was probably the first time that I wished I'd had siblings because Dad couldn't or wouldn't talk about it and oh, I had Geoff but there was no one else.

No. Was your father generally a 'shut in' person? Would they talk about your own disability and how did they treat you, you know, 'get on and do it' or?

They were really supportive. Anything that I asked to do, to try, to tackle – even if they thought I was going to come a cropper – they would let me do it and they were

there to pick up the pieces and support me. And they were really supportive of me and they did try to make me an independent...

Good.

There were other children maybe a bit more disabled than me at Claremont. And I've seen it many a time, where the mother won't let go, won't let other carers come in and when something happens to them, the child – although they might be 40 by then – it's just so traumatic...

I know.

Because that's all they've ever known.

That's one of my fights at the moment where I'm working.

Yeah, I can imagine.

Anyway, so Kevin went to school. Did you take him to school or did he...?

At that time we lived right opposite the school playground.

Aha.

We'd moved yet again because of my husband's job; it was still in Bristol but it was further out and we lived right opposite the school, so it was wonderful. We used to get up and walk him across the road and come back. It was really handy.

Did you hear of Kevin getting any stick from the other children about his mother?

Yeah, he came home and I mean both of them at times have said, you know, 'The other children think you walk funny', all the rest of it. But I mean I just sat down and

explained about the disability. I mean it wasn't anything unusual to them because I was just 'Mum'.

Of course.

I used to have to use a wheelchair if we went like a long shop or if we wanted to go on a country walk, so Kevin – up until we had Katie – I mean he used to stand on my footplates when he got tired. And of course then Katie came along and she took place on my lap if I 'ad the carrier, so that was a bit of an argument because he didn't like being pushed off the foot plate but I mean he was getting too heavy by then. But I guess that was the only time.

Good.

Yeah, Katie was quite good and it was as she got older she got more awkward.

I think girls always are.

Yeah. [Both talking together.]

Yes 'cos with Kevin when he hit puberty we had about nine months I guess of him being, you know, moody and slamming the doors and then that was it. [Coughs.]
So I don't know, boys just don't seem to go through it like girls do. No.

So when the children were growing up did you have time to pursue your own interests or hobbies or social life?

Yeah.

You did?

Yeah

Good.

I [aeroplane overhead] went to the AGM of the local Spastics Society group and volunteered to be an assistant secretary, then I worked my way up to vice-chair.

Was this over, oh, where was it?

Well, originally when I was involved with it we were meeting in people's houses.

Ah, yeah.

So then I became chair of it.

Yes

For seven years I think. So that was good, yeah. We set up a group for parents of newly diagnosed children because there still wasn't an awful lot around. And it was just a support group; they used to meet, they used to talk, it was a social thing. And you know, by listening to other people's experiences or if they had a problem and then, you know, one would say, 'Oh yeah.' Yeah, it was really good time so... I got involved with Scope national. I used to go – to what was then the regional meetings – down in Exeter, up to London. We applied to be a trustee and the day I should have gone to London for the AGM I fell down the stairs and cracked my head [laughs].

Oohh.

So needless to say I didn't get in either but yeah, very involved with local and national Spastics Society at that time.

And has this continued or not?

I still had a quite a gap but well recently got back involved with the local group and I was doing an awful lot and I've cut back a bit over the last year, two years.

You never got involved with the West of England Coalition of Disabled People?

Not at that time, I did about five – no it's only since I've been here – about three, four years ago. I actually volunteered to help in the disability advice centre because when the children were small – Katie was six and at school and they both went to school where my husband was a caretaker, so after school they just stayed with him – I was the manager of the disability advice centre down in Canningford House for, I don't know, about nine months I suppose.

Was that down St Paul's way?

No, it was the one before that

Oh.

In Victoria Street. Then I moved over to the other wing and I became part-time secretary to one of the social workers and I worked my way up. I then worked for one of the managers and then we were moving over to St Paul's area because the new office had been built and my manager at that time who was the regional administrator then... and we went in and chose all the furnishings...

Good

And you know, the panelling and all the rooms and the whole lot because it was just an empty shell. So that was really interesting to go round and pick furniture and make it as nice an office as we could on the budget we were given, yeah.

So you actually had paid employment with Scope

Yeah, [both talking together] for about two years and then I was at work one day and I felt really dizzy and they said, 'Well you can't work like this.' So someone drove me home in their car and somebody drove my car and got home and just had to go to bed, felt terrible – excuse me [coughs]. Got up the next morning, I thought, 'Oh I feel terrible, so giddy.' And went to the doctor's and she said, 'You've got a 'flu virus.' I said, 'But I haven't got a cold, I haven't got a sore throat, I haven't got a runny nose. No, no' I said, 'all I've got is this head.' 'Yes, it's a 'flu virus.' So this went on and on and I was getting weaker and weaker and I was spending more and more time in bed and I went back to the doctor's after about five weeks and they started then saying it was post-viral fatigue. So I didn't know a lot about it, she said, 'You know just rest up, drink', all the rest of it, so did that. After three months I finally felt able to go back to work. I did for another 18 months. In the meantime I'd read a magazine article and it was about post-viral fatigue syndrome, which was really another name for ME. So I went back to my doctor's and I had a battle then and she said, 'No you haven't got ME, it's post-viral, it's completely different.' I finally... there wasn't really an expert, she said, 'Well there is one chap.' And apparently he was a tropical diseases expert and for some reason he got lumbered with all these people saying, 'I've got ME', so I went to see him. And we had a chat about the symptoms and he said, 'Well if I said you've got ME, you know, how are you going to react? What are you going to feel like?' And I said, 'Well, relieved in a way because I'll know that I've always been right all along and at least I know what I'm dealing with.' So he said, 'Well, yeah, you've got ME.' I struggled physically for two years and then it came to a head when I had to have another three weeks off work and in the end I was dismissed on grounds of ill health, which really upset me.

I'm sure it did.

Because I loved my job, I didn't want to leave and I said, 'Could I have a year's sabbatical? And you know, I'll come back after that. I don't want to leave.' But no.

That's terrible. Did anyone put forward the idea you should have a PA to help you do the work?

No.

Would that have helped?

Probably because it was quite a physical job

Yes

Again it was a big office. Having the ME, although I was still walking, I certainly didn't have the energy and well just the energy and couldn't maybe walk and do things as much as I could. I left there in the March and by then, I don't know whether I gave up and gave in or it was what I should have done in the beginning because I ended up in bed 24 hours a day. Just laying there with your eyes shut quite aware of what was going on but if people looked in it was a terrible feeling.

[End of Track 2]

Track 3 [Tape 2 Side A]

Tape two with Kay Bath on 12 April.

So I was just days and days like that or getting up, you know, for really short periods of time just to eat and it was a struggle to get to the loo.

What year was this?

[Whispering.] Katie was eight. It was 1990 I first went ill, this period of it started in '93. It just went on for months; you gradually clawed back little bits of the day. And an armchair up in the bedroom to save me the effort of going down the stairs, you know, to the lounge. So I just used to sit out there for half an hour and then I might have to go back to bed to watch telly or just lay there. Then when I was able to get up more and more we found that I could walk less and less and then from walking independently I started walking with one stick

No one offered you any physiotherapy at this time?

No. One stick, two sticks, one tripod stick, two tripod sticks and a zimmer frame. And anything outside the front door involved a wheelchair then.

Could you drive?

No. I just didn't have the energy. [Clears throat.] It's not just energy it was the strength in your arms, a bit, an odd feeling. And when I talked about it to the doctor and she said, 'Well if you had to have a secondary disability, ME was the worse one you could have because it's just not compatible with cerebral palsy.' She said, 'In a way it's become the primary one [clears throat] because it's ruining your life now and you have to rest and be far more inactive than you were but by doing that you lose your mobility with the cerebral palsy.' So it's really hard because I think all my life I

struggled and it was a struggle – excuse me [coughs] – and the last thing I want...
And I used a wheelchair occasionally but I did not want to be in one full-time.

It must have seemed so unfair?

Yeah.

So did you, you know, seek any alternative treatment or...?

I went back and saw Mr Glover after two years and he suggested – by then they were beginning to be a bit more aware about it because this is four, six years on I suppose – so he tried me with Prozac and that was horrendous. They tried me on one mil a day of the liquid stuff because I had tried it in tablet form before and couldn't take it. And one mil [coughs] and then two mils. And I was in a restaurant in Bath having a cup of coffee and my husband went off to the loo and I picked my coffee cup up and I did have this almighty spasm that I don't normally and tipped the coffee all over myself. [Laughs.] I was absolutely mortified.

Of course.

Yeah, I can sort of see it. So we gave that up and apart from the rest there wasn't any real... I tried herbalism, I tried acupuncture, I tried cranial osteopathy and none of it really worked but sometimes you just have to give something a go and then you're probably grasping at straws. But I mean some things did [both talking together] work for some people and if you don't take a chance and try it you don't know.

Did you do any swimming or...?

Yeah, that was another one, they tried me in the hydrotherapy pool and I thought, 'Oh that's going to be lovely, you know, in the water, gentle exercise.' So we went for the first one and she said, 'I won't do a lot with you, you know, we'll just gradually get things moving.' I said, 'Yeah, OK then.' I got home and I just fell asleep in the chair,

went to bed. I was then in bed for three days; it was another two days of fairly restricted activity. Basics I was feeling OK-ish as I did at the time, they said I went back for hydrotherapy, went home, went to bed, four days in bed. Went back the third time and I said, 'I can't do this.' I said, 'As gentle as it is, it's too much.' I said, 'I'm going home and having three, four days in bed to come here for an hour.' I said, 'I can't do it. I want quality of life. I'm not going to lay in bed anymore.' So we gave up the hydrotherapy as well. And I found a support group and that was quite good in hearing other people's experiences and [door opens and third person enters room]. Can't remember where I was now.

You had just told the physiotherapist you couldn't go on with hydro.

No. I was going to tell you something; it's gone right out of my head...

And you had tried some alternative things

Yes.

But without success. [Both talking together.]

Oh that was it, the support group. And I went to the support group and...

[Break in recording.]

I mean, you know, we parked right outside and there was a little path and were able to cope with that. And we got inside her house and we had coffee and we had the meeting and people were starting to go and I'd been there quite a few times, so I knew a lot of them. But there was a new lady that joined us that day and I stood up to go home and she said in rather a loud voice, 'Oh my God! I 'ope I don't end up like that.'

God!

Not realising that I obviously had cerebral palsy [laughs]. As well as the ME [coughs]. So...

That must have made you feel great? [Laughs.] God!

Yeah. I mean I knew the reason and I'd given it a go, and I did enjoy meeting the people but they found it very hard to understand from my perspective because it was different for me than it was for them.

Mmm.

Because you have to spend so much energy and effort in walking or doing anything with cerebral palsy, so having the ME on top it was something you know...

Terrible

Yeah. [Both talking together.] So I think that's really, you know, why it got so bad because I just had to put effort into trying to be me and plus having this on top.

So during this time your children were in their early teens, how did that go? [Both talking together.]

Yeah, Kevin was fine; it didn't really seem to affect him a huge deal. His life still went on because he was 11 when I contracted it, so he was like 15, 16 getting to about half way through it. And he was starting to make his own life; he was preparing to leave school. He decided he was going to college and learn catering. Katie was about 12 or 13 and she was eight when I first had it and it was hard on her in a way and in another way it wasn't. I was always there; she always knew where to find me. I've always got fond memories of her coming in and cuddling me on the bed and she'd lay there for hours and we'd talk and we'd watch soaps and discuss it and all the rest of it and learn what she did at school. And I thought it was OK and I thought she was coping and I had a lot of support from my mother. And it wasn't until she was about

18, 19 and there was a mother/daughter row about something trivial and she yelled at me, 'I'll never forgive you for being ill.' And I said, 'Well why?' 'I couldn't do the things with you that other girls did with their mums.' We couldn't... I mean we did on my better days, go shopping but yeah everything was fairly restricted. But you know I just didn't do the things with her that she wanted me to do.

Have you got over this row or is there still this gulf between you?

There is still a strained relationship I'd say between me and Katie. That's partly because of that, although I think about a year, two years ago I actually brought it up and she sort of dismissed it and said, 'You know that was when I was 18 and...' but I don't know, it was still there. A lot of it these days is for other reasons because obviously my life went on; '98 to the year 2000 were absolutely horrendous in my marriage and my husband left me. He walked out and although Katie was living with me in the house at the time, she decided – although she never talked to Dad much when they were living there – he was the best thing since sliced bread. And I was the one left to live on my own.

Yes, kids can be very hurtful can't they? And I'm sure with the gender issue of mother/daughter on top of everything else. [Laughs.]

No, it's not a good combination. And then well, I met someone, somebody I already knew, going back 20 years. We had sat on the same committees, so it was just like a face and a name but I met him partly through West Bay, my holiday the respite centre organised. But I can tell you that another time.

Yes. I think maybe we should wind up now.

Yeah.

It's been very interesting; I hope you have enjoyed talking about yourself?

Yeah I hope I haven't just wittered on

No, it's very interesting. Thank you.

[End of Track 3]

Track 4 [Tape 3 Side A]

This is a recording with Kay Bath on the 31 May, second meeting. We will be continuing with her employment and further education, yes? OK.

I think we covered when I was at work with the bank didn't we?

Yes.

I stayed there for two years and then I went to work for the family business, which was an electrical contractors. So I helped in the office with my aunt and we did all the administration work and everything. That was about for another year and then I left for the birth of my son. I was fine about being pregnant; it was everyone else. My parents were quite concerned. I did have contact with the Spastics Society – with the social worker during all that time, which was really good, a big help. She found out information for me, so we had... and trying to help solve problems. So we managed to locate a changing table that was high enough for me to be able to stand and lean against and change Kevin.

Before you got that far what was the attitude of the medical profession when you went in for the birth or up to the birth?

I can't honestly say I was discriminated against. They were – considering that was 29 years ago – fairly OK. The only time they took my disability into consideration was obviously going to be during the delivery. They didn't think that my hips and the shape of my spine would be contusive [conductive] to a natural birth, so a caesarean birth was planned two weeks before my due date. So that was quite good and after the birth I was left or given as much help as any other new mum and that was it. I mean physically sometimes they had to take into consideration that I couldn't move in the bed afterwards, as well [as] somebody who was able-bodied. But on the whole really it was quite a positive experience.

Good.

Yeah. And then took him home. I got quite upset when he was at home, about the first week and my mum came round 'cos I asked her to come round and help me bath him and I couldn't do it in the end, I had to let her do it. Because I couldn't stand, hold him with one hand, use the other hand and balance, all at the same time. So I got quite upset that I couldn't bath him then. And we used to live in a split level bungalow – because I couldn't walk at that stage – which only had a... you went in the front door and there was a second bedroom and the bathroom, and there was a kitchen with like a bar and then a small dining area. And then you went up five steps and you had the lounge and then the main bedroom. So when Kevin was small, it was all right when Geoff was at home because he'd carry Kevin up and down the stairs but when he was at work I had to stay in the downstairs bit... tiny room space, which was fairly small and quite sort of claustrophobic really. Just so that I didn't have to carry Kevin up and down and because the bathroom was downstairs and the kitchen... and I didn't want to leave him up there if I was down there making a drink. So that was a bit awkward and sort of not very nice being sort of down a bit in a well really because you had a bit of a wall

Did you solve the bathing problem or did your mother go on giving...?

Well, either my mother or my husband did it yeah. It was different when he was older.

Yes.

But no, when he was newborn they did it. Yeah, but everything...

Nowadays do you think there could have been some other solution like with a perching stool?

Yeah.

And things?

I think there'd probably be either more help or advice [both talking together] around now than there was then and I also had to give up my Invacar, which I loved.

Of course, yes.

So and I think it was at least a good year, 18 months before I learnt to drive a car and again at that time there wasn't a huge amount out there to help either – that or I couldn't access it – to help people drive. So I looked in Yellow Pages under driving schools and driving instructors and a gentleman right over the other, well not over the other side but quite a few miles away in Westbury on Trym said in his advert he could teach deaf people to drive, so I thought, 'Well, if he's willing to do that then maybe he'll take me on [laughter]. So I rang him up and we had a chat on the phone and he became my driving instructor.

Good.

And he was brilliant because I passed first go.

Very good.

So yeah but I know there's been a lot of bad press about the Invacars but I did love them, although when they gave them to you it was really... I had mine when I was at college and the guy brought it in – 'cos we had a garage underneath the girls' block – and he brought it in and he said, 'Oh,' you know, 'sit in and I'll explain everything to you.' And I said, 'All right.' And then he was going to shut the door and he said, 'That's it, off you go then.' And I said, 'I can't do that.' And he said, 'Oh all right.' And he shouldn't 'ave but he perched down the side and sort of saw me down to the end of the road and back again and then that was it, you were out on your own.

Gosh!

It was.

Scary!

Yeah because that was your first bit of driving.

Yes.

And you didn't have anyone with you telling you what to do [both talking together]. I mean I read the Highway Code [laughter], so I'd know what road signs and things were but you had no real formal instruction.

That's fantastic. So were they battery driven or electric on charge?

They were petrol driven, yeah.

Petrol.

Yeah but they were lovely 'cos the seat would slide to the left door or slide to the right door so you could get out either side [both talking together] depending where you parked.

Yes.

And they were small and they were easy to park and yeah, they were lovely.

What's the longest journey you did in one?

Coventry.

Really?

Yeah.

So that really was freedom.

Yeah, I had it when I first started working at the bank, so going down town every morning in it. But no, it was lovely, you could go to the shops, I could go anywhere. And I didn't have to rely on my parents for a lift.

Yes.

So that was...

Very important.

Yeah

To be self-sufficient.

Yeah... Kevin went to nursery when he was about two and a half, for a couple of mornings a week because the health visitor thought that he didn't mix with other children, so that to socialise him he ought to go to nursery and she got him into a state nursery for a couple of mornings a week, as I said. And that was great; it was a lovely place. Although that came under threat of closure, so we lobbied and I actually went and met our MP at the time at one of his open surgeries and lobbied for it not to be shut because it was so important to keep it open and it did.

Good.

They did keep it open. When Kevin was four and a half I had Katie, who again was born by caesarean but only a week before my due date. So two weeks before my due date they said, 'Whatever you do don't go into labour.' [Laughs.] And I started to and

we called an ambulance because it was the end of January and there was a blizzard outside. That's when we used to get snow sort of two or three feet high and this ambulance had to come and take me. And we were going down this steep hill and – I think he was on HTV – a local television news presenter was trying to cycle up the hill in this snow blizzard. I always remember the ambulance driver saying, 'Look at that silly idiot.' And then I recognised who it was. But it was quite funny [laughs]. But I got sent back home...

Oh dear.

It was all false. And Katie was born when they wanted her to be born. And yeah, Kevin was quite good about her, quite accepting.

Was she an easy baby or not as easy as Kevin?

Well, she was an easy baby. Kevin used to have – especially when he was about 18 months – would have terrible temper tantrums and Katie didn't but then as they got older she got worse, [laughter] especially in the teenage years. And Kevin was pretty laid back and so from what they were in the beginning they both sort of swapped over really. And I don't [both talking together]... It seemed easier I suppose because I had had one baby at the hospital, although there wasn't discrimination but I guess there was some concern. It didn't seem to get that so much the second time. Yeah.

Were you living in Bristol at the time?

Yeah, apart from the couple of years in Coventry, I've lived here all my life really. So...

So when the children at primary school... were you aware that they had any problems from other children, having a disabled mother?

Yeah, they would come home [coughing from interviewer] and say – because I used to take them and pick them up and when Katie was about two we moved and the school was literally across the road from our driveway, so I just used to walk them over. So we were known in the area, so it wasn't too bad with sort of fairly local children but once other ones in the playground who didn't know, who didn't live around there, yeah they would ask Kevin, you know, 'What's wrong with your mum?' And sometimes they'd sort of say names and that and he'd get a bit upset about it and we'd have a sort of chat.

Had you been upfront with them from the beginning about what had happened to you and why you were in that chair?

I wasn't in the chair at the time.

Or why you had mobility problems?

Yeah but I was always just 'Mum' really.

Yes, did you [both talking together] find that any of the teachers had interpreted your condition in some other odd way?

No.

Good.

No.

Good.

They were quite good.

Because I found out why my second son used to get so worried whenever he was ill because someone had told him I was like this because I'd been ill.

Ooh. [Laughter.] No, they knew that it was when I was born and that there had been problems and that was why. No, I was fairly upfront with them. Yeah and then when Katie was about six, seven I decided to find a part-time job. I was doing voluntary work for the local spastics group at the time and decided I wanted to do more and I went for an interview for the information centre in Bristol, disability information centre. And I got the job of manager of the little unit, which was based [sound of cup and saucer on table] inside the Spastics Society regional offices.

Very good. Was this a forerunner of DIAL or something?

Yeah we were part of DIAL [both talking together]. We didn't actually call ourselves sort of DIAL Bristol [both talking together] it was always the disability information centre, which is still going today. It's now called DIAS but yeah. So there was a little team of three, we were all disabled. My two colleagues were wheelchair users and myself and one of them, we used to do house visits if people really couldn't get in to see us at the office but we covered everything, mostly benefit advice but housing and adaptations, cars, holidays, you know, the whole spectrum of life really. And I stayed there for about, I don't know, 18 months, two years and then I became a part-time secretary to a social worker within the Spastics Society.

Good.

And then I moved.

Who was that? Oh sorry go on. [Laughs.]

Oh that's funny, her name's gone.

So you were employed by the Spastics Society?

Yeah.

And you never had any problems getting employment with them?

No. Well I was known because we were housed within their offices. They had a big L-shaped floor of the office and there was this tiny cupboard with double doors that opened on to the corridor and a single door that opened into the Spastics Society offices, so that we could access their kitchen. But clients didn't have to come through the Spastics Society place; they could just come straight in through the double doors. But when the job came up I applied for it the same as everybody else but I got the job.

Good.

Yeah and gosh, stayed there about four, five years all in total. I worked with the regional administrator very closely and when they built the new office in Easton [ph] we were the ones who had to sort out, you know, partition wall and carpet and everything, furniture; so that was quite exciting. We moved over to there – by this time I was senior secretary – so I worked underneath the regional administrator. If she was out of the office then I was responsible and we used to have trainees in, so I was responsible for making sure that they had work and looking after them... any problems. And I worked then for the personnel officer and the manager who was in charge of schools and units like that in the south west.

Good. I'll just check your...

[Break in recording.]

It was during this time in 1990 – so about halfway through my employment – that I became ill in the January. Got sent home from work because I was really dizzy. Went to the doctor's the next day and she just said, 'Oh it's a flu virus; go home, drink plenty.' And I said, 'But I haven't got a runny nose, you know, no flu symptoms, just

this dizziness.’ And she said, ‘Yeah but it’s still a flu virus.’ So this went on for about three weeks and I went back and they were then saying that I had post-viral fatigue. So I sort of accepted that and I was off work initially for three months but then I felt recovered enough to go back [sound of cup being placed on the table] and I did. But over the next two years it was a real struggle because I obviously hadn’t got over this virus and after about a year I’d read an article in magazine that post-viral fatigue was ME and I tackled my doctor and she said, ‘No.’ And I pestered her and pestered her and then said, ‘Well, I want another diagnosis. I want a proper diagnosis.’ So she referred me to a consultant in tropical diseases who somehow – in Bristol – had got landed with seeing the ME patients because it was coming to the fore then. And we had a chat and he examined me and he said, ‘Well what would you do if I said you’d got ME?’ And I said, ‘Well, I’d be quite relieved to know what it is and how to deal with it.’ And he said, ‘Well, that’s what you’ve got.’ I still carried on working and December ‘92 I went to my doctor about infected toe [laughs] and she said, ‘How are you coping?’ and I just burst into tears and she signed me off for another month. And to put it politely that was the end of my time with the Spastics Society.

Did you choose to finish or did they say, ‘Sorry...’?

They said, ‘Sorry...’ It did go to a panel in London and they were quite upset that a disabled person was going to have to leave but yeah, they dismissed me on grounds of ill-health. Even though, you know, I said, ‘Could I have a sabbatical for a year?’ just to get, you know, to make sure that I get the rest and everything and no pressure and that, you know, come back then but I was refused. And I have to admit I was very bitter.

I’m sure you were. [Laughter.]

Because I didn’t want to go and I really loved my job.

Mmm.

I mean I hope, I think I was good at it and I just really enjoyed it. Yeah, the challenges every day was different and 'cos I was dealing, you know, with two different subjects but then you 'ave to do things, you know, for other people in the office or you had to fill in; it was different every day.

Were any of the executives disabled in those days?

No.

No, I know. It used to make me so angry. I felt that these people were earning a load of money on my disability [laughs].

Yeah. No, out of the floor all my colleagues were able-bodied.

I know.

We had people with disabilities on reception and there was obviously people with disabilities running the advice centre because they'd moved with us when we went to Easton but...

I'm surprised you've had a disabled person on reception because I was in and out of that building in Easton, usually in the evening because we had meetings of the West of England Disabled Peoples...

Oh right, yeah. [Both talking together.]

Coalition there and you know, there was a guy who let us in with a disability. He said he was only allowed to work in the evening when the public didn't see him.

No, we did have one or two during the day.

But I suppose one or two that looked and sounded fairly normal, in inverted commas?

[Laughs.]

Yeah.

Yes.

Yeah, so that really was the end of my working life. I don't know whether it would have happened or it happened because I wasn't fighting to continue my life but the ME got really bad and I was bedridden for quite a few months. With the cerebral palsy if you don't use it, you lose it and that's what's happened over the last sort of 14 years.

When you had ME were you offered any physiotherapy to help keep you, you know, your muscles...?

I was offered hydrotherapy...

Yes.

And I thought, 'Yes, that will be good. It will be really gentle exercise but I'll still be able to do it.' But I went on the Thursday I think and the first week... Friday...

[End of Track 4]

Track 5 [Tape 3 Side B]

Friday, Saturday, maybe Sunday I'd be wiped out, then the rest of the week I'd pick up and by Thursday morning I was feeling fairly OK and I'd go and have another session. I think I stuck it for four weeks but by the time the four weeks ended – I ended it – I was just wiped out all week; it was having a progressive effect, so I had to stop that even. So I went from walking independently to using one stick, then having two sticks, then tripod sticks, then a Zimmer frame to keep myself walking and then the majority of the time, I used the wheelchair.

How did you manage as a mother? Were your children teenaged by now? Were they any help to you or didn't want to know?

Kevin was 11 when I was first ill and Katie was eight and it doesn't appear to have had a big effect on Kevin. I think because he was that much older; he was at secondary school and he was getting on with his life, he had things to do. Katie it had a much bigger effect on. And I thought it was fine because she always knew where to find me and we used to spend lots of lovely evenings snuggled up on the bed and either watching programmes or she'd tell me 'er day or problems she had or you know, we sorted a lot of things out by chats. But it wasn't until she was about 18, 19 – we didn't normally row but one day we did – and she did say, 'I can never forgive you for being ill because you were never there for me.' Which I thought I had been.

It's very difficult, if I may say that? There's nothing you can do at all.

No because well, it was the truth I suppose. I mean I did what I could and on, you know, good days, if Geoff wasn't working or whatever, well by then he'd given up work. His job had been halved from 42 hours to 21, not long after I gave up work and so he took the decision to be my full-time carer, which he did for seven years. So if I was feeling good he was there, so we could go out and do something but it usually meant – it was never the next day it was always the day after – it would hit me and sometimes you just thought, 'Oh well, blow it, I'm going to go out and do this today

even though I know that, you know, two days time I'm going to be in bed for a day or two.' But it was the price you had to pay otherwise you'd just stay indoors 24/7 and...

Did you suffer financially as a family?

Yeah, it was tough 'cos we were living on benefits. So there wasn't a lot of extra money.

For football boots [laughs] or high fashion?

High, oh yeah, high fashion [laughs] the pair of them high fashion. It's the time when all the brand names were starting [both talking together] to come in and you weren't cool.

Doc. Martens. [Laughs.]

[Both talking together.] But I never gave in on the trainers.

Yes.

So sometimes I'd say, 'Well, I'd pay this on a pair of shoes, so you can have that, you put the rest with your pocket money or whatever.' So that's what used to happen.

Were you able to go on holiday as a family or did they go on school trips?

They did go on school trips but really it was down to my parents who helped us. Although by the time I was ill, my father had died; he died 57 of lung cancer. So that was quite hard and as I'm an only child this was no one else to share the responsibility with because my mother went to absolute pieces. So was I working then?

[Whispering.] I was working, so I used to call in and see Mum. I used to try and go down there every day or we'd have her up on the weekends and 'cos she just had two outfits, one was a grey skirt and a purple jumper and the other one was a brown skirt

and I can't remember the jumper. And every time I went down she had one or the other on. So I let it go on for a little while and then one day I went in her laundry bin and got the other outfit out and threw it away, so she had to wear something else [laughter]. She did start picking up but it was a very tough time because we were a very close family. I mean Kevin remembers him; Katie was only two and a half when Dad died, so she doesn't really. She's got a few but not a lot. Whereas Kevin used to go in the garage and work, do woodwork with Dad and out in the garden and that's a shame. It's tough yeah, it was tough. Because I s'pose they had a bigger input in our family life I think than the average family, you know, Geoff got on with them really, really well, so yeah.

And so the children were growing up into teenagers and did they study? Did they do well at school? Did they decide on careers or?

Yeah, Kevin found schoolwork hard; it didn't come easy to him. And when it came to choices of subjects he couldn't choose. He thought he wanted to be an architect but also he was keen on catering. So we met with the head and she said, 'Let him pick the subjects for architecture and then, if when he leaves or he gets to 16 and he decides that's not for him, he can always pick up catering at further ed.' And that's exactly what happened, so he went to what was then Brunel College and did a three-year catering course and that was it; that was his niche in life. He'd found it because he was excellent. He didn't really want to be the chef in the kitchen side of it; he wanted to be the front of house. He liked to be meeting people, dealing with people and he was good at that and when he left there he got a job as a waiter in Harvey's restaurant, which was one of the best in Bristol and we were quite chuffed with that. It was [telephone rings] it was quite good and he loved it. It was really long hours; he'd go in at nine in the morning, he might get an hour or two off in the afternoon but he used to stay down town, it wasn't worth coming home and then he wouldn't finish weekday half eleven, twelve o'clock at night but a weekend [knock at door] it was about two in the morning.

[Break in recording.]

So it was really long hours, really hard work and we were sort of quite concerned but he absolutely loved it. And after about three years there his chef thought, you know, 'It's time for you to move on and move upwards and progress your career.' So Kevin came in one day and it was, 'I've got a job in Scotland.' I said, 'What?' This was about September he said, 'Yeah, I'll be leaving next August.' [Laughter.] And we said, 'OK.' And it went on and the months went on and I kept saying, 'Well don't you think you ought to go up and see this place?' 'No, no, chef's sorted it, it will be all right.' So about a month before had to go, I was really pressurising him now, so my mum gave him her Air Miles and said, 'Fly up.' So he flew up and he said, 'I'm not taking my working gear.' And it said that you would experience the service in our restaurant and he thought he was going to have a meal in the restaurant and I said, 'I don't think so, I think you ought to take your working gear.' 'No, no, don't need that.' Anyway, in the end he put it in and he went and he rang me, 'I don't like it up here. What am I going to do?' And he was up there for the weekend, it was a big hotel set on a golf course and he 'ad to stay up there 'til the Monday morning. And he hated it. And he didn't get a meal in the restaurant; they actually wanted him to work, so they could see what he was like. So mother was right, as she always is. But that was quite funny. But the night he came back, a fella who'd moved down to the Portsmouth area who was the original chef when Kevin first started but he left after three months, said 'There's a job down here, would you be interested?' And Kevin went down the following weekend and got the job, so within a month he left home. Luckily he had a place with the job, so that was a big wrench.

It must have been, missing him.

Yeah 'cos he's your first born and...

Yes.

We've always had a really close bond. Not saying I haven't got it with Katie but no, that was quite a tough time.

Boys are different.

Yeah.

Is he still in catering?

Er... no. [Laughter]. Well, he met one local lass and that was it, apparently you know, this was the one. And unfortunately she fell ill and that was a really difficult time for him, well and me because she wasn't diagnosed as having ME but her symptoms were very similar. And he ended up taking her out in a wheelchair. I think he had only been going out with her properly for about two months before she fell ill. And he used to ring me up and I know one day... and I did realise the connection that he was feeling because he knew how much I had deteriorated and he'd met this girl and he liked her and then she was presenting with the symptoms that his mother had. And he was having to go through all that again. So that was quite upsetting, I mean he was really upset but she got fit and well after about a year and then dumped him.

Oh no. Oh, how bitter for him.

Yeah but time went on and he met a lovely girl, Leanne, who already had a son from a previous relationship, he was five when Kevin met him. And they've since married and they've got two sons, so I've got three grandchildren by Kevin and Leanne and my daughter married and I've got...

Kevin is still working in catering [both talking together]?

No, he worked in the restaurant which is similar to Harvey's. And then because of meeting Leanne and Jordan and having a family life outside of work but still working these horrendously long hours and he wanted more time to be with them. And then when Leanne fell pregnant with Sam it was even worse because he said, 'The baby's not going to know me.' So he left that restaurant and went to work in what they call a

gastro pub which sells fancy food but in a pub surrounding and he stuck it for about six months and he said, 'I've lost the heart. Catering's not for me anymore.' So he gave it all up and he's become a private hire driver. He did about six weeks normal private hire for a company and then they had companies within the company and one of them was executive travel to airports and I think because he is really good with people they've asked him, so he now does executive runs.

Very nice.

Yeah and he seems quite happy. He gets to choose the days he wants to work and the hours he wants to work really.

Do they live near you?

No, they live in Portsmouth. So yes, quite a way. Katie still lives in Bristol.

What does she do?

Well, she also did the catering course...

Oh did she?

At Brunel and because of Connor now she just does two days a week in a hotel on sort of reception, booking duties.

So she has a son too?

Yes.

And you've got four...

Four grandsons.

Boys?

Yeah.

Very nice.

Yeah and a funny story is – to do with my disability – is because when I go down and visit Kevin because I can still walk the few steps, his house isn't very disability friendly and there's a couple of steps and a little path to their front door. So I get out of the wheelchair and I hold on to Kevin's forearms and he holds on to mine to steady me to get into the house. And the last time I was getting back to get in the car and we got halfway down this little path and Kevin cracked up laughing and bent over, which wasn't a very good idea when he was holding on to me [laughter]. And I turned round and Sam, who's just two, had hold of his mummy's arms and he was walking out backwards out of the door, pulling Leanne out [laughter]. And he did it right because Kevin does it backwards all the way up the steps and everything, Sam did it as well. So it's obviously the norm and you know, the men walk backwards [laughter]. He's a funnyocity [ph]. Yeah but well, I suppose they've always known me, so they, it's like my children; they've just grown up with it. I mean Sam and Tyler are a bit younger but Connor, they all think it's great that Nanna's in a wheelchair and whizzes about everywhere. But he's so good, I mean to get to the sink and he sort of stands on my footplates between my feet, so that he can reach his hands, you know, wash his hands or reach something and... His favourite game is my helping hand and he picks the magnets off the fridge with it, puts them on the floor and then puts them all back and that's his favourite game. So, it has its uses.

Yes.

Yeah.

Good. So what about life nowadays?

Life nowadays. My first marriage broke up.

Oh. Was that after you'd recovered from the ME?

Yeah, I had had two really good summers when I felt... normal. And then the winters, things sort of slided back a bit but then the second summer things didn't slide back and they remained fairly good. I still had to be careful not to overdo things and even nowadays, you know, every now and again I think, 'Well I'm going have a really early night' or 'I need a rest in the afternoon' or something. But on the whole it was much better than what it was. And then Geoff decided to go back to work, which was fair enough because I was feeling OK, I could look after myself during the day. The house had been adapted to take the wheelchair downstairs.

May I just interrupt? About adaptations, did you have to go through social services?

Yeah.

And did you have to wait years?

Yes [Coughs.] Excuse me. He decided to go back to work and had given himself a year to do it and so he said, 'Well I'll just look, you know, for jobs.' So I rang up the OTs because I said, 'Well I can't manage with you at work on my own with a zimmer downstairs. We really need to bring the chair in otherwise I'm going to be exhausted at the end of the day.' So I rang up the OTs and it was a 12-month waiting list for one to come out.

Yes it's really iniquitous. I mean it's a system imposing an even bigger handicap on people with disabilities.

Yeah. And the bad thing – excuse me [coughs] – was he applied for a job and he got it. So within three months of him making the decision, which meant I still had nine

months for an OT to even come out, so it was making the best of a bad job really. So I was in the lounge, so he would prepare my lunch and leave it in the kitchen, so I could go and get it, a flask of water and a tea tray in the lounge for me because we couldn't use the wheelchair downstairs, we had two separate rooms. Then the OTs finally came out and we went through all the business of applying to get the wall knocked down and a door put out to the back garden because we had a patio outside the dining room but we also used to access it through the kitchen. But that was when I was walking, so we wouldn't get the wheelchair through the kitchen door, so it all took time and then they finally did the work. So I had a year of having the access, with Geoff at work, which was brilliant because I could get in and out the kitchen, into the dining room, into the garden. I was back to being totally independent. But all this time there was me feeling great and he obviously wasn't and I kept saying, 'Go to the doctor.' Because he just couldn't be bothered and even though I was feeling better I still used to go up to bed early. I had a chair in my bedroom and I used to sit up there and watch telly even though I didn't actually need to rest. And I used to sort of shout down, 'Could I have a cup of tea?' or I used to just say, 'Geoff' and it would be, 'Tut, what does she want now?' [Clears throat.] So on one day he just had enough and he got up and went. [Clears throat.]

Did he ever explain verbally why he went or did he just go?

Well, I thought he was suffering depression and he went to the doctor and she said, 'No.' And it went on a couple of months and it had got worse because he used to do shift work, so if he was on an early shift he would come home about four o'clock. He'd go straight upstairs he'd put pyjamas on, come down, make a cup of tea, sit on the settee, watch telly and really didn't want to move. One week when it was really bad we lived on take-aways for a week. So I sent him back to the doctor and he went back and saw the same one that said he didn't have depression and she again said he didn't have depression. Then he went and I had to admit, it was a relief because things weren't good. But to be honest nobody outside the family knew how bad they were 'cos that's me I tend to bottle things up. And I don't know, six, four weeks after he left he did go to the doctors and he was diagnosed with depression but by then it was

too late because I'd had four really bad years with the attitude against me and although it wasn't I guess, really him, the damage had been done. So that was the end of that really.

Do you ever see him now or do the children see him?

No, we're good friends.

Or does he see his grandchildren. Oh good. [Both talking together.]

Yeah, we're really good friends. And I've married again and I've moved right over to the other side of Bristol, which is totally alien [laughter]. I've been there four years and bits of it are still alien to me.

Yes, I know Hangrove [ph] is very different from Westbury and Henbury and that way.

Yeah, my second husband's disabled, whereas my first wasn't.

How did you meet your second husband? What's his name by the way?

Trevor.

Trevor.

Well, I knew him I guess, 25 years ago

Good heavens.

But we never sort of talked. We both sat on the same committee, local group. And then he was married as well. Then I went into the local respite centre for respite when

the ME was bad and after the first year the activity organiser there used to organise an annual holiday for four of the clients and...

[End of Track 5]

Track 6 [Tape 4 Side A]

So I was invited to go and Trevor also went on that first holiday and we acknowledged each other because we knew each other briefly but I was married. He was married and my recollection is we didn't have an awful lot to say to each other during that first holiday. And then three years later because they were short of people because of the limits put on them, I was invited to go over to France again because it was a brilliant, brilliant holiday. I remember the first time we went sailing...

Mmm.

On these little catamarans with net between the two holes [hulls?] and we used to sit on the net, so we used to get very wet bottoms. But oh, the feeling of just skim... they used to take us... it was an absolutely enormous lake. I don't believe we ever got down to the bottom of it. And just to be skimming along, it was a brilliant sense of freedom. Absolute... can't forget it. It's incredible to be there and your disability didn't matter, that was wonderful. But we used to do quite a lot of activities and join in with sort of the local activities in the village, if they had a fete while we were there. And so I went again the second year and coincidence, Trevor was also picked the second year and by this time he was divorced and my marriage was virtually on the rocks. So we tended to talk more this time and we agreed afterwards that we would keep in touch. Because his wife had been able-bodied and she left him, so he knew what I was going through, which was great because nobody else did. So he used to ring me up or I used to ring him up and have a chat and then Geoff left and about three or four months after Trevor rang up one day and said, 'Would you like to come to lunch on Saturday?' And I thought, 'Well why not, I haven't been anywhere for a while.' So I booked a taxi, which wasn't as easy as I thought and managed to get over to Whitchurch and had lunch and we just hit it off brilliantly. And I got home about just gone nine [laughs] and my mother phoned. When I got in I did the one four seven one thing [both talking together] and I knew she'd phoned, so I thought, 'Oh well I'll leave it, I'll ring her in the morning.' So about five minutes later the phone goes. Bearing in mind I was 47? Yeah, 47. 'Where the hell have you been?' 'Out for lunch.

I told you I was going out today.’ ‘I’ve been worried about you. I thought you’d be back home at six o’clock. What’ve you been doing all this time? Where’ve you bin?’ [Laughter.] And I thought, ‘I’m not standing for this, I’m 47, my mother’s not going to speak to me like that.’ I said, ‘I don’t have to tell you anything, I’m 47.’ I said, ‘I don’t have to answer to you where I go. I’ll talk to you in the morning when you calm down.’ ‘Huh!’ she went and slammed the phone down. So on the Sunday morning, about half past nine, quarter to ten, the phone went and it was Trevor and he said, ‘Would you like to come back for lunch today?’ So I said, ‘No, I better not, Mum’s playing up.’ And I related Saturday night. So I phoned her up and she was still off with me [laughs]. So I phoned Trevor back and I said, ‘Is the offer for lunch still on, if I can get a taxi?’ And he said, ‘Yes.’ So I said, ‘All right, well I’ll say yes, if I can’t get a cab I’ll let you know.’ And I did have a bit of ringing around to find a wheelchair accessible cab but surprisingly I got one and for a return, so I went over. That was that.

Was he reasonably independent where he was living?

He had a three-bed bungalow on an estate built by Habinteg.

Mmm, yes.

So it’s a mixture...

Yes.

Of housing. He’s in a wheelchair and he’s got cerebral palsy and his disability’s more severe than mine and he does have slight speech problem.

Did he have a PA at that time too?

Yeah, he did. He had four and the one I met that weekend became a really close friend to me and I got on really well with her. But I have to say because I didn’t have PAs I

lived independently. And when I went over to visit or stay the weekend, or a week whatever, it was fine because it was short spells and then I would go back home and I would have my peace and solitude and privacy. And then we talked about me moving in because he wouldn't have managed in my house and the PAs were a worry to me because there's somebody in the house.

Yes, it's intrusion.

And I found it really hard. I mean they're really nice, they accepting me, you know right from the beginning, you know, Trevor's partner. And you know, he asked them if it was all right, you know, for me to move in. And I do benefit from them really because when they do the washing they don't just do Trevor's they do mine and obviously when they cook, they cook for both of us. And they've sort of got sort of specific tasks, so one who does the cleaning then obviously I benefit from that. But even now, four years on, I still have a huge problem with it.

Mm. I'm sure you do, yes.

In fact I suffered a spell of depression because of it because we've got a big sort of kitchen/diner/lounge, really big room. We turned the smallest room into an office for the computer. But it is, you know, the traditional little box room but there's not a huge amount... and then there's our bedroom and the second bedroom is still kept for Olivia, who's Trevor's daughter and she's only 12. And she used to live in Bristol, very close and we used to have her a lot but two years ago her mother moved down to Torquay, so obviously Olivia went with her. So we only have her every other weekend and sort of weeks in the holiday; so her bedroom is still, you know, as she's left it really.

How do you get on with her?

Very well. She's a lovely girl and...

Good.

I mean I enjoy doing things with her and that but because she's so much younger than my children and I've had my family and I've done that and I know I've got grandchildren but you sort of hand them back afterwards [laughs].

Yes [laughs].

So when she's there and now she's just starting to go through the teenage angst and I'm thinking, 'Ohh.' But I did say to her, was it? Oh she did the trick that Katie always did; clean clothes on the bed for her to put away and the next day you find them in the dirty bin. I brought them back up, I said, 'You won't get one over on me' I said, 'I've had Katie' I said, 'I know all the tricks.' [Laughs.] I says, 'So don't even try.' [Laughter.] But she just laughs. So no, we get on all right. But there again, in a way, it's another intrusion. It's not that I don't like her coming up because I do and I enjoy her company but all of a sudden she's there 24/7, certainly for a weekend and then it could be for a week or two weeks at a time and it's having to adjust again.

Yes.

To another person in the house.

How long do you have the PAs for?

Nine 'til six every

So does Trevor need help in getting up and getting washed?

No, he'd still cope, starting to have a few problems but at the moment we're coping but I think that's something else I need to get my head round, is that there's going to be more help coming in, not less. So I don't know, I'm going to have to find ways to cope.

Have you room to extend the bungalow?

Yeah, we're sort of thinking of that, just sort of looking at the options really, see what we can do. And also he lost two PAs quite suddenly and so we've had a fair few gaps, which means we use agency, so it's like a whole stream of people.

Yes.

And some you get on better than others.

But it's explaining all over again each time.

Not too bad though, they try to send people, so we have sort of a regular little group but occasionally if there's an awful lot of sickness or leave or whatever then you end up with staff that come in, maybe only come in twice a year and it's, you know, 'Where's this? Where's that? How do you want this done?' So yeah.

Do you find that they're well trained about disability rights or do they try to impose their ideas on you?

There is sometimes a lot of assumption on their part that when they go I do absolutely nothing, whereas although the kitchen isn't brilliantly adapted I can use it all and I still like to cook. I just don't cook every day but I always enjoyed cooking. And like the other Saturday I had to ask someone to get a mixing bowl out before they left because the last time I used it somebody put it in a totally inaccessible place. And I know one night I tried to get something out of the cupboard because somebody had put something that I use on a regular basis on the top shelf, right at the back.

It's so irritating.

And it's just [both talking together]. Yeah but it's just assumed that they come in, they do their job for the chunk of the time and they think that when they go out the door, I don't know, that fairies are there or whatever. But I still need to do things.

Of course.

Because I get my own breakfast, so I need to access crockery.

Yes.

And certain things.

And I suppose you bake the occasional cake or something?

Yeah. Well, I mean I made scones on the weekend, so yeah I get a fit and I think, 'Oh I'll try that.' And sometimes I will cook the meat part of it, so well I don't know 'cos Trevor and I like, we have a lamb steak with a redcurrant gravy and he likes the way I do it, so I insist on doing it. And then they just have to do the veg bit. And I think the first time it was a bit, 'Hmm. It should be my job to do all the cooking' but you know, at the end I just buttered her up and said, 'Oh you know, that was a really good team effort and... thinking, 'Why am I doing this?'

Yes, absolutely.

It's my kitchen.

Yes, what about shopping?

One of the PAs used to do it and I was getting more and more worked up about it and I said, 'Let's do it on the internet.' And Trevor said, 'No, can't do that, she'll be offended.' So anyway, she went away for two weeks and I said, 'Right, I'm doing it. Don't care what you say I'm doing it.' [Both talking together.] So I started doing the

shopping on the internet, [both talking together] which gave me control over what we had yeah. [Both talking together.] And she came back off the holiday and I said, 'Oh you don't have to do the shopping today I've ordered it on the internet.' 'Oh thank goodness for that' she said, 'I hate Tuesday mornings, having to go down.'
[Laughter.] So that's it. It worked out well.

So Tesco's deliver do they?

Yeah and Sainsbury's but I use Tesco's.

Yes, so do I but I resent the charge.

Yeah.

However...

But for me it's a small price to pay.

Yes.

To get my independence back.

Oh yes.

'Cos I can shop and you know, if there's bargains then I can get them [both talking together] whereas she didn't always pick up on that.

No.

So she'd just stick rigidly to what was on the list, whereas I don't always.

No. Good.

Yeah.

Good, yes and they do your cleaning for you?

Yeah.

That's useful. [Laughs.]

Yeah.

And they come in at weekends?

Yeah. At the moment we don't have a regular one, so we've got free time because we've just got agency coming in for meal times to do the meals, which is hard if Trevor wants sort of stuff done but we're just in the process of advertising for a couple more.

So are you handling the financial side of it yourself?

No.

Or not?

The direct payment [both talking together] do the payroll, yeah.

Oh I see they've got someone doing it, yeah.

Yeah, they just send us back [both talking together].

So that takes all the problems out of...

Yeah.

Insurance and...

Yeah, they...

Things like that [both talking together].

I mean you pay a charge a year but in a lot of ways it's worth it. They just send us back an envelope; we have to get the time sheets in by a certain date. We get the envelope back [both talking together] payslips are in there, copy payslips are in there and I just write the cheques out and then put them in their envelope and that's it.

Good.

So yeah no, I don't want to have to do all that; I did that years ago. [Laughs.]

So how long have you been married altogether now?

We've actually been married 18 months and I've actually been living over there three years but I was going out with him a year before that.

Have you had any holidays?

Yes.

How do you manage when you go away?

Well, so far we've only gone to a Vitalise centre.

Aha. Which one?

We've been to three of them. We've been down to Churchtown, in Cornwall.

Yes.

We've bin to Jubilee Lodge up in Essex but the favourite one is Netley Waterside at Southampton.

Is it?

Yeah [both talking together].

Because I'm just helping one of my key students go there this year and I'm wondering how he'll like it?

We love it down there.

Yes.

Because it's in a little village and because Jubilee Lodge doesn't really have a relaxing sort of room, so you go in and you've got reception but then there's this huge lounge with a proper bar and there's a bank of windows and there's two lots of double doors which go out on to the patio and then it's all lawns and flower beds right down to the Southampton waters virtually. There's a path that goes down and right at the bottom there's a gate that you could get out and then – it's a bit bumpy in a wheelchair – but you can walk along this little path and you know, the pebbly beach bit is just, you know, right there and the water is... And if it's a grey day and you decide you don't want to go out on the trip then you're quite happy sat there because there's stuff going on and it's a nice room just to sit in.

Good.

And they put stuff on in the evenings; there's entertainment.

When you went did you pick a week according to your age group or did you go in just generally?

[Both talking together.] No, just a general week, yeah. The first time we went down to Churchtown we just picked a week. And when we got there on the Wednesday in the evening and people were saying to us, 'Which group are you in?' And we said, 'No we're not in a group, we're here on holiday.' 'Oh yeah but it's wildlife or garden week.' And we said, 'No we haven't come for that at all.' So this went on all Wednesday evening, Thursday morning, in for breakfast... a couple, 'Oh are you in our group? We're garden week.' So 'No, no, we're not here for any of that.' And one of the instructors finally comes up and says, 'Which group are you in?' 'We're not in a group; we're just here for the holiday.' And he said, 'No, you've got to be in a group.' He said, 'It's garden week or wildlife week.' And we weren't told when we booked up, so we weren't very happy 'cos we were in wildlife week. [Laughs.]

Oh dear.

But I have to admit the instructors were really good and did accommodate us, I mean we went in with them, they went to Newquay zoo one day and we were quite happy to do that and I think another day they took us into Plymouth, so that they could go to the aquarium. So say for wildlife birds... Trevor and I could go shopping or up on the Hoe or whatever we wanted to do. So they were very good and it turned out to be a good week. But yeah, that's the favourite one. I think it's the...

Are you going there this year?

Yes, September.

Good.

And Christmas.

Oh very nice.

Yeah well, the first year we were together we stayed home because my mum... but she wasn't happy about me going out with Trevor at all because she loved Geoff as a son and she thought, surprisingly, that it was my fault. So that first Christmas she got invited and she went and had lunch with Geoff's mum and dad. So I saw her for about five minutes outside my front door 'cos she wouldn't come in but I told Geoff, 'You stay there.' But he wouldn't, he came out and he made my mother speak to him.

Has she accepted him now?

She unfortunately died two years ago.

Oh I see.

But yes, we made our peace and she realised that he did make me very happy.

Aah, good. What about your children? Have they accepted him?

Kevin right from the start, yes. He's been brilliant, he's accepted Trevor totally into the family and in fact Olivia was a bridesmaid at Kevin and Leanne's wedding. Katie, no. She's better than she was and...

It would be surprising if it had been smooth sailing. I mean daughters normally are very attached to their fathers.

Yes she, you know, well she was 'teenagery' and you know, I used to get, 'Mum, would you ask Dad if he'd pick me up at so and so.' And then I'd get, 'Kay, would you tell Katie to tidy her room' or put the washing out or whatever. And that was how

they communicated – through me – and yet he went and all of a sudden he was the best thing since sliced bread. So...

Very hard.

But she's coming round slowly. [Laughs.]

And her son?

Oh Connor loves... yeah.

Yes.

Well, Trevor's always been Trevor.

Yes.

And he's got no problem.

Good.

No.

Does Trevor work?

No.

No.

No. He used to work with his parents on a sort of smallholding really where they lived in the village and they had quite a lot of land attached to it. And although his father worked they had massive greenhouses that they used to bring on flowers and veg and

then sell it or use it for the family or whatever. So seen lots of pictures of that. Trevor when he was younger driving a tractor and... yeah.

How do you manage your garden at the moment?

One of the PAs does it.

I see.

She likes gardening.

Do you have many raised beds or anything?

No.

No.

No, I just like looking at it. [Laughs.]

Yes.

Well, it's still our garden, you know. We say what goes in it and what we do with it, so she's just the physical bit of it.

Can you go out together say, to a garden centre?

That's the other. You have a car [both talking together].

No, I don't.

Oh no, you don't.

I gave up driving.

You go by taxi or?

Well, that's...

What about Trevor, does he?

That's the really difficult thing.

Yes.

To find a taxi for two wheelchairs.

Yes.

If it's something like a hospital appointment then his PA will take him and I get a taxi to the hospital, so a lot...

[End of Track 6]

Track 7 [Tape 4 Side B]

Trevor sits in a car or must he sit in a wheelchair?

No, he can transfer to a car, so in a lot of ways it's easier for him to get places and to get a taxi really because you know, long as he says, 'Well I can transfer and take the wheelchair' it's not too bad.

So your son can never take you both out together?

No.

Yes. And so you can't really do things on the spur of the moment.

Oh no.

They've got to be planned? [Both talking together.] [Laughs.]

Yeah.

Are there many that can take two wheelchairs?

No. When we went down to Portsmouth for the wedding, luckily within Kevin's firm there was an adapted minibus, so we went down by train, so that picked us up and took us to the hotel, which is where everything was being done. Anyway, so once we were there that was fine and then he picked us up again on the Sunday and took us back to the train. But in Bristol it's harder. I haven't found one yet sort of similar that would do it. Naively, I thought in a way being with another disabled person in some senses would be easier. And I think it is on an emotional/mental level because you both understand about each other, so you know, if I'm having a tough day physically or whatever then Trevor understands and vice versa but you know, to physically do things as a couple is not so easy.

No. Can you go out wheeling distance, you know, to the local shops?

Yeah, [both talking together] he's got an electric wheelchair, so he's around the house he prefers his manual.

Yes.

And just sort of scoots it. But when we go out the front door then he'll use his electric one. So yeah, we can go to the shops or for a walk.

How do you find the local shops? Are they accessible?

Ours is; it's an ASDA.

Ah yes.

And there's a little rank of independent shops and they're all accessible.

Good.

And because obviously living on the Habinteg estate there's a lot of people with disabilities around so... [Both talking together.]

There's dropped kerbs?

Yeah, everything and you know, people in the supermarket are really friendly and you know, quite understanding because they get so many of us going in there really at various times. But no, they're really helpful and but they're not pushy.

No.

So yeah, very good.

Good. So have you anything else you'd like to comment on or, you know, living as a person with a disability? Do you think about trying to go back to work?

Not now.

Do you feel you... no?

No, I think I did more at the beginning and then physically I just couldn't do it and it was the same with driving. I had to give the driving up because of the ME because I just didn't have the strength in my arms. And I've thought of going back driving but I mean, that was 10, 12 years ago and roads and traffic have just changed so much I don't know that I'd want to go back out in that. It's not you; it's other people.

Yes.

And it's just mental out there [sound of gas bottle]. I'm lucky I've found an independent taxi. She did have a radio from a company and she picked me – I think I'd been going out with Trevor for about four months – and she picked me up. She was just by chance the driver that day assigned to that job to take me over to Whitchurch. And she was doing independent work as well, so I've used her ever since. I've known her about three and a half years.

Good.

And she's brilliant. 'Cos we just hit it off.

Good.

We clicked and we chatted all the way over and that was it. But I mean I'm lucky, a couple of weeks ago I had to find a taxi and I was told on the Tuesday I needed one,

and I rang up one local firm and I was told, 'Is it an electric wheelchair?' 'Yes.' 'We can't take them.' And I said, 'Why not?' 'Because our drivers have got to go on this course about disability and none of our drivers have done it, so we can't take you.' So I rang round and I found somewhere else. On the Saturday, a situation arose and I hadn't planned to go out and I needed to go out, so I rang this firm again and it was, 'Is it an electric wheelchair?' I said, 'Yes and don't give me that about the course' – because I'd found out in the meantime, I'd rung licensing – I said, 'You can still take me.' I said, 'Yes your drivers have to go.' 'No, no, it's not the course; we can't take you because it's health and safety.' And I said, 'All right, what's this one then?' And it was, 'It's health and safety on our drivers because if they put you in a London cab they have to bend and that to belt you in and it could hurt their back and injure their back, so they won't do it on health and safety grounds.'

Oh, for God's sake!

And I did ring the chap at licensing and it is all a load of rubbish and he is going to investigate that one.

Good. This is the local licensing is it?

Yeah.

So are you going to have a campaign about this and, you know, the lack of cabs that can take two wheelchairs?

Yeah, I must admit taxis...

Because this is iniquitous that you two can't go out together.

Yeah.

Which is really a basic human right. [Laughs.]

And also where I live we've got low-level buses and I nearly got trapped on one 'cos I went to pick it up from where I was and the driver had parked far enough away that if I tried to get up there the wheels would have gone down. So I said, 'Would you back the bus up and bring it nearer for me and then I can get on?' 'No' he said. So I said, 'Well, would you come out then and drop the ramp for me?' 'No' he said, 'if I do that I'll hurt my back.' I said, 'No you won't, loads of other drivers have done it for me.' I said, 'Would you drop the ramp for me, please?' Quite nice. 'No' he said, 'I'm not going to do it.' So he just wasn't bothered that I couldn't and he wouldn't help me on the bus. So there was a young guy in the queue and he manhandled this chair on to the bus; he tipped it back while I drove it on. So I got on there and I got my mobile, they had the customer numbers, so we were driving along and I'm thinking, 'So when we get to town how the hell am I going to get off?' So I rang customer service for the bus company while I'm on the bus and I told them, 'I'm on this bus going into the centre of Bristol' and explained the problem I had with the driver getting on and I said, 'I'm really worried that I'm going to be on this bus all day because...' [Laughter.] So she said, 'Could you wait 'til you get to Union Street and see what the situation is and if not, ring us.' So we get to Union Street and he does it again. He parks too far away and he wouldn't drop the ramp. And I said, 'Well I'm going to stay here and block your doorway.' I said, you know, 'Please let me off.' And he absolutely refused. He just sat there and looked dead in front of him, so he didn't have to look at me.

What a pig!

Yeah. Luckily I don't know if he stayed on or what but the same guy was on the bus and he came and helped me off the bus. And as soon as I got off the bus I had this number that I needed and I rang them straight away. I said, 'Well I'm in Union Street, your driver refused to put the bus near enough, he refused to drop the ramp.' I said, 'The young man who had helped me on at Whitchurch was still on the bus,' I said, 'luckily for me.' I said, 'Otherwise I would have been driving around in the doorway of the bus all day.' So she said, 'Can you tell me the number?' So I gave her the number and the route and everything and she said, 'Well this isn't on. We're, you

know, trying to promote disabled people using the buses. We will do an investigation but you won't know the result.' And then I had to get back from town to home and I thought, 'Oh God!' So I got to the bus stop and I think the word had gone out with all the bus drivers, 'Watch out there's this woman down town [laughter] electric wheelchair and she's trouble.' Although I wasn't, I just exercising my right.

Of course.

So I was waiting in the queue like you do for the bus, my hand out and he drew in, it was perfect, he couldn't have got nearer that kerb if he'd tried and the same when we got home. But he wouldn't talk to me. As I got on the bus I said, 'Thank you.' And as I got off the bus I said, 'Thank you.' And he just blanked me.

Disgusting.

So...

You should have made a thing of it with the local paper.

Yeah.

Because it's just not good enough. Which bus company?

First Bus.

First Bus. That's the kind of thing that publicity can do a lot for.

Yeah. But I mean, you know, you've got the right to go to a taxi rank and pick a taxi up and that's just not as easy. I mean I got there one day and the first cab was accessible and I said, 'Could you take me to Whitchurch?' 'Well, I don't know,' he said, 'how heavy is your wheelchair?' I said, 'Oh come off it' I said, 'that's, you

know, first time I've heard that one.' 'No' he said, 'I can only take a certain weight wheelchair.' But he took me to Whitchurch 'cos he knew I was about to make a fuss. [Laughs.]

Yes, you can see it's nothing out of the ordinary and you're certainly not like one of the big 20 stone fellows.

No.

It's really bad isn't it? All these years after the 1996 Act. [Disability Discrimination Act.]

Yeah.

We're still having this problem.

Yeah.

Yes, so in spite of legislation, really your human rights are still not good at all.

No and I didn't realise, well I s'pose it's only recent years – well last eight, 10 – that I've had to use public transport that you realise how bad it is and it's disgusting. The railway, touch wood, no I've had good... with them [both talking together].

Good.

I haven't had a bad one; they're always there with the ramp and the conductor or whatever nowadays, they always say when I'm on the bus and the first time they come round, 'Where is it you're going to?' And I tell them and he says, 'Well I'll radio ahead and let them know.' I say, 'Well I have booked assistance but they always ring ahead for me to say, you know, 'Yes she is on this train' and they're always there.

Good.

The only problem you have is when you initially get on the train; everybody's put their luggage...

Yes.

In the disabled space.

What about getting into your local surgery or to the dentist? Is that OK?

The surgery is low-level, accessible except for the doors; they're really heavy and you have to pull them and it's only like a single door. I can if the door's right back then I can get the wheelchair through but it's not ideal.

No.

But they are building a new surgery for everything, so hopefully I've put down, you know, automatic doors.

I mean I was appalled at coming in here, how heavy the door is.

Yeah and the switch being up as high as it was.

Yes.

It's quite a reach [both talking together] for the Scope button, so things have changed since I was younger but there's still an awful lot...

Oh yes.

Left to do, a huge amount, yeah.

So have you anything more you'd like to add or comment on? Raise the flag?

No transport's my pet thing at the moment [both talking together].

Have you flown?

No.

No.

No, not since I've been in the chair.

OK, well thank you very much indeed. This will be very useful and interesting and it will be added to the archive in the British library.

Oh, right. Good.

Yes. Thank you. The end.

[End of Track 7]

[End of recording]