Thalidomide: Liz Lash (2012)

Ruth Blue interviews Liz Lash for the *Thalidomide: An Oral History* project.

This is Ruth Blue interviewing Liz Lash on 19 October 2012 at her home in Polegate for Thalidomide: An Oral History project. Liz, could you confirm that you've seen and signed the copyright and consent forms?

Yes, I have.

And would you mind starting by telling me your full name, age, date and place of birth?

Elizabeth Audrey Lash and I'm fifty two years old. My date of birth is the eleventh of the fifth 1960 and I was born in Eastbourne, East Sussex.

Thank you. The first part of the interview is mostly about your childhood, your birth your family and school life, and any medical interventions you might have had. So first of all if we could talk a little bit about your family background. Who are your parents, what line of work were they in and do you have any siblings?

I have no siblings, for almost a biological reason in that sadly my parents were only actually married for four years. They married in 1956, they met at Kings Mead Preparatory School in Seaford where they were at the time both teachers. My father previously had been a Major General in the Arab Legion, serving under Glubb Pasha. The only reason I mention that is because the family background that he came from, added to the pressures that my mother was later to be under. My mother was teaching there although her heart was very much in the State system, but she needed to get out of another job because she didn't like the head and the system was very different in those days. As I say, they married in 1956. My mother was then thirty-two. They had a very different view on having babies at later ages in those days and so she didn't think she would have children. My father also was sixteen years older than she was so therefore the thought was there probably wouldn't be any children. But low and behold, she became pregnant in 1959, and I rolled along in May of 1960. Now unfortunately, three months previous to that, when she was six months pregnant, my father was diagnosed with terminal cancer. He had cancer of the throat and oesophagus. The feeling probably was, talking to my mother, because she was happy to talk about it, not happy, that sounds awful …

Open?

Open, that's a better word yes. That he had probably known that it was around for quite some time before. The best way I can tell you what happened is to tell you what she said to me which was the surgeons opened him up to see what they could do and found that he was riddled with secondaries. I'm using the word secondaries, that isn't the word that was used then, but I'm using the more up to date language. And they closed him up. It was obviously a sad and fraught and difficult time. My mother … I will need to talk about her parents later and her relationship with her siblings … but at that moment she was very isolated. My father's family … their two families didn't gel because … the only word I can use is almost we're verging on the upper class with my father's family, and my mother's family lower-middle if you like and it was quite a big divide and that made life even more difficult.

My mother was prescribed Thalidomide, Distaval, to give it its pharmaceutical name at the time, not for morning sickness like the majority, but for insomnia. Now she was … I'm not surprised she was suffering from insomnia at the time, when you think what she was going through. I think, when I think of the time pattern, that it was probably because, when I look back, that it was probably around the time when my

father was first becoming ill. She knew she was pregnant at the same time, and also there were issues with her own family, and so it was a very complex time. I was born in the May and for the first month of my life we lived in the cottage on the estate of the prep school which used to be the bicycle shed, it was built on, so my father said his child spent her first month in the bicycle shed.

Subsequently it became obvious that my father was, I use the word terminal, it wasn't working for my mother living there with him and with me, set aside the fact that I was severely disabled anyway so there were the complexities of that and who knew what was going to happen. And so they moved in with my father's sister who had a large house in Lushington Road in Eastbourne and that was where my father lived and my mother stayed with me, I think, but I'm not entirely sure whether she stayed with him or lived with her parents in Seaford, I never asked the question, I'm not quite sure what happened.

Life being more complicated, my grandparents, my maternal grandparents had actually been in Canada at the time of my birth. Their belongings, they were travelling, their belongings had all been in storage and there was a massive fire on the morning of my birth and their belongings all went up in smoke, so it was just an unbelievable chain of events. My father eventually died in the August. Now, there's a gap here, I do not know exactly where I was living between the August and the December. Where my mother was with me. I'm not sure, it wasn't a question I ever asked. But I do know that in the December of my first year of life, December 1960, my mother moved with her parents to a bungalow in Westham, which was a three bedroom bungalow, two reception rooms, I'm telling you that for a reason to make you smile in a minute, I can assure you, a large-ish piece of land and a garage for the princely sum of three thousand pounds.

It's just impossible to imagine isn't it? It's just impossible.

And initially they needed a mortgage, which is even funnier I think. I love that bit of the story. They actually moved in, because that's the sort of thing my grandparents did, they were quite mad the pair of them, on Christmas Eve. They would do that. So there we were, mother, widowed, with severely disabled child, and parents.

Okay, I'm going to take you back a little bit as well, but that's a very dramatic series of events …

It's not bad. It's a start! I said I came in with a big bang but …

I was going to ask you, do you know how long your mum took Thalidomide for?

A relatively short period of time as far as we can work out. Now this is where I need to jump forward I'm afraid. I only discovered in 2009 that she took it. She was very ill at the time, I only had a small opportunity to ask her questions, and what I needed to ask her at the time were practical pertinent questions because it was distressing enough for her to be asked, it was a very, very difficult situation, very awkward. I had to go back and look through her medical notes to find it because we needed the evidence for the Thalidomide Trust. Or I needed the evidence I should say. I was thinking we because I was thinking of Dave and myself because he was being so supportive at the time. And it was certainly recorded that she was prescribed it, and she certainly knew that she'd taken it. Her sister also confirmed to me before we'd had that conversation that she'd been prescribed it. She had always known that I was Thalidomide and had been told not to tell me. Families … it's a very complex one this one.

That is very complex. I've not heard that before.

That is very odd. Both her younger sister, who's thirteen years her junior, my aunt, to whom I'm very close and who knows all about this. She lives in Canada but I've been in contact and it's fine to mention her name and anything else because I thought I ought to check with her, and also my mother's older brother who died a few years ago, he also knew, and I have discovered that when he came over here, when he knew that he was terminally ill, ostensibly to say goodbye, his real reason was to say to my mother "Have you not told Liz yet? You really ought to tell her she's thalidomide. How much she's missing out." That's what he actually came here to do and I didn't … I mean I have no reason … it's very difficult … it's a very odd one.

One of my questions is were you ever able to discuss with your parents their decision to use Thalidomide. So you did, but you did it when your mother was ill?

My mother took it for … she went … this is when we have to start tracking it. It's fortunate that I understand a lot about medical things for my own interest. I'm reasonably au fait with medical language and things. I actually had to go back through my medical notes, and the surgery were absolutely fantastic. Fortunately they found all the previous notes, they were brilliant. A dreadfully difficult situation for the GP because the GP was the same for myself and for my mother and so he was … awful for him because he's known all these years and of course he couldn't tell me.

And he was the person who prescribed it for your mother?

No. The prescription … now it was actually prescribed by a doctor at a hospital in Brighton. She was living in Newhaven at the time, obviously before she got married, and when she got married and moved to Seaford she stayed with this Kitty Kendrick and she had sent my mother to Brighton Hospital, I am not quite sure why. And it was the doctor there who prescribed the Distaval because it was a different doctor's writing, that's how we knew it was … and it's only mentioned once, and then a bit later on it's got something about 'review' and that's all it says so we assume that she was on it, as far as she can remember because I did ask, she said "I certainly took it for, it must have been about a month." If it's the right trimester, there we are, it's certainly good enough for the Thalidomide Trust so … she certainly knew that it had done the damage, there's no … once I had faced her with it, she didn't deny it, although she denied it to me for fifty years.

So had you asked her before? Had you suspected and asked her at other points in your life?

No, never. Because I had always believed what she'd told me, and she'd always told me that I wasn't thalidomide. She even went to the point of saying that she had talked to the then GP, which is another one, what else it could have been. Whether she was trying to justify to herself, I have no idea, but I wasn't able to follow up that bit, it wasn't important at the time, I had to pick what was important. Because we had a two-hour conversation with her about it, and then I went with the notes and sorted all that out. My investigation started in February 2009 and I was subsequently accepted in the Trust in the December, but there was an awful lot of work in that time and I had the conversation with her in the August.

And did she explain to you why she hadn't told you?

That's a really difficult one. I mentioned family pressure. Now, this was huge. Her mother … so careful how I put this … was not a very pleasant person. She was also, sadly, someone I think who had mental health problems that, as was the case in those days, was not diagnosed. Seriously, I would say, verging on paranoia. That's not a joke, I'm absolutely serious using that word. I'm using it in its medical sense, and she put incredible amounts of pressure on my mother and when everything started to bubble, mid to late sixties and early seventies, she put a tremendous amount of pressure on my mother, "Don't get involved, don't get involved. The papers will get involved, people will know," which was always her thing. She ruled my mother.

By this time, her younger sister, to whom my mother is very close, my mother pretty much brought up her thirteen year old younger sister because my grandmother didn't want another baby, this shows what a strange person she was, she told her own daughter how much she'd tried to abort her, how she tried to get rid of her. I don't know how anyone gets over that. I'm sorry, I didn't get on with my grandmother, I didn't like her. From a young age, living in the same house, I saw how she treated my mother and how she made my mother feel. And I couldn't deal with it. I'm too direct and very different and I couldn't deal with it, it was so unkind. That pressure was coming from that side. At the same time … and her sister by this time living in Canada. Both her siblings were now living in Canada and the basic reason was to get away from mother. That's the basic reason they'd gone. Her older brother had epilepsy and basically was made to feel ashamed of it by his mother and also by his father to a lesser extent although my grandfather, I think that was pressure. And couldn't cope … he was more like his mother, but couldn't cope and he went in the early fifties, he went to Canada, not long after the end of the war really. And meanwhile my mother's younger sister Diana married an architect who got a job in Canada and they emigrated in '63. So my mother now has got the pressure of her mother, my grandfather who is a very different person, sadly, lovely man, he died in 1967 just before it all started so he was out of the picture. So it's my mother and her mother.

Now my father's family there were certainly two members of his family, I think looking back, probably were viewing this slightly differently. But I don't know. They are not still alive, I can't ask them questions. Because my mother was thirty six when she gave birth to me, because my father was sixteen years older than she was, all that side of the family were a lot older than they should have been is how I put it. So my aunts and my uncle, particularly my uncle who I was very close to, was my father's brother, who was a Franciscan Friar, he was a bishop for a time in his life. I was very close to Bill. I think that he was possibly the one who might have tried, and also my father's sister who was a nurse up at St Thomas's, she might have tried. But it's an interesting fact that where there were other members of the family, that I got left money by both of them when they died, and it's almost as if, because my father didn't have any money to leave when he died, I forgot that bit. Not that they're trying to make up for it, I don't mean that but there was a definite, sort of, you know, but I think that's quite interesting. So, with the pressure there was on her, and then I think as the years went on, she just pushed it away.

I think it gets harder, sometimes, to go back on something once you've started doesn't it? And then it means you've got to admit you've lied, and nobody wants to do that.

And also, in her eyes, I was making a success of my life. She didn't see or understand, and right up to the end, to her, the disability world was a frightening one that she didn't want me part of. Sadly she couldn't see that actually there's a positive side to it too, and that you can, for want of a better word, straddle, which is what I've learnt to do. But I came to that very late, because I was kept away. Some of what she did was

absolutely right. When it comes to education, what she did was absolutely right and I've got no, you know, because she would not have me go to what she'd call in inverted commas "a special school," she was going to have me educated mainstream.

We're going to go onto that in a minute but first the birth. I'd like to know about your birth, how the birth went, and what happened immediately after your birth. Do you if your mum was sedated or …

I know very little I'm afraid. All I can tell you is that they took me away and I think they did that with most disabled children, mind you, I think they still do it sometimes. And it was a case of I know there's something wrong with the baby. She gave birth not in hospital but in a maternity home, a word you don't hear anymore. Upperton Road Maternity Home, Eastbourne. And she was being looked after by a doctor who was a close friend of my father's, and whose name has just jumped out of my head which is awful because he was a lovely man and he went on to found our hospice St Wilfred's Hospice. Kent, Basil Kent, sorry, a brain cell went for a moment, just died for a moment there!

Well you're doing a lot of remembering so …

I know, and I don't think about these things very often so … and he was the one who came and said to my mother your child is very … you have a baby who is very disabled. I added to the confusion, by, if you like, they thought initially I'd got hydrocephalus and then decided, excuse me, you're allowed to laugh, a very big head. Some things don't change! And I also … I had terrible trouble feeding, right from the word go because I'd got pylorostenosis although that wasn't diagnosed until a few weeks later because that is not normally diagnosed initially. So there was a lot of kerfuffle going on. I know very little about what actually happened straight afterwards because the problem was, there was my father being brought in … he was ill … Basil Kent was a friend, so it was all a bit cliquey is the only word that springs to mind. So I really can't answer much of that because I don't know.

So your parents never spoke about how they felt when they first realised you'd been born with a disability?

My mother said … I can tell you that … and I also will tell you that my grandmother did one of the few really good things that I do know about … my mother said that somebody said to her "Will you keep her?" Now I'm not entirely sure who said that but I think from what she said, unfortunately sad though it is, it was a nurse in the nursing home, sounds par for the course in those days I'm afraid, and my mother said "Good gracious me, what do you mean keep her?" She said, "I was absolutely furious. You weren't a stray dog, you were my daughter. You were Liz." Because they'd already decided that Elizabeth was what I was going to be called. And her view was that what mattered was that I was going to be what was left of Noel, sorry, that was what my father was called, I haven't said that. His name was Norman Oliver Lash, but he was Noel – quirky things they do with names sometimes. And that was always the thought. Because if I had been a boy, I was going to be Nicholas Oliver Lash, which was another family name, so that then I could have been Noel myself if I'd wanted to later in life. But I think that the feeling was, she certainly never waivered from … I was never going to be one of the ones who was put away which was something else that was said to her. My grandmother … I have always said, and my mother doesn't think that I'm wrong on this, because we did talk about it, didn't think I'm wrong on this … that, and it may have been my grandfather's idea … bear in mind that people stayed in longer when they had babies in those days … the second day she was in the nursing home after I was born, my grandmother sent *me* flowers, which for her, was quite a remarkable thing to do and to my mother it was like somebody acknowledging that I existed.

But she was always determined … the only slight problem that this then developed into was an obsession with me which was a bit unfortunate, because her life then became me.

Oh an obsession with you? Yes, I see what you mean.

And I think … hindsight's a wonderful thing … but I can see that looking back and I think that's important to record because I think it was to do with her own mental health issues and I think also it gave her something positive to focus on, which I totally understand, with her husband dying, and knowing that she was going to be living with her parents, and her sister whom she adored was on the other side of the Atlantic, and you've got a child who is going to need a lot more support.

Can you describe what level of impairment, for the sake of the recording?

Yes, I thought you might want to … well, when I was born, that's slightly different to what it was subsequently … when I was born, both legs very short and bent upwards, I mean my mother told me that she couldn't keep my feet out of my nappies.

Bent upwards this way?

Yes, round, bent upwards. My left arm, I have no thumb on the left side at all, the wrist was very bent, my left arm was actually bent up towards my shoulder. The shoulder is very mal-formed although, in fact it's typical, I wasn't aware of this at the time, and my shoulder blades are also typical of Thalidomide. My right shoulder, its problems really have come from over use, it's not too bad, the arm is a little short, but not short like the left arm. My right wrist doesn't bend properly. I don't have a thumb, but there was a residual flap of skin, that had to be removed. It was actually on my finger, not my thumb. I'm fortunate in that my ears are not affected. Internally, that was not to show until later. There is damage internally, but that wasn't, at the time, nobody knew it was there. Yes I had pylorostenosis. The muscle thing that was put right by surgery when I was about eight weeks old. And it was that causing trouble in 2009 when it caused me to start looking so …

So would that operation for the pylorostenosis, would that have been your first medical intervention?

Yes it was.

Do you know how long you were in hospital for?

I have no idea. But I was a tiny baby, I wouldn't like to say. I don't know. Probably a few days I would think.

And did you have any other medical interventions? Early on?

Not in the first few months of life. The first things would have been when I was about eighteen months old when they started, via manipulation, to bring down my left arm, and I was in a heavy cast which on more than one occasion I nearly knocked my poor mother out with it. That was actually quite successful … and that was done locally, that's the important thing; that was done at, no longer around, St Mary's Hospital in Eastbourne. I don't know who did it, I haven't any idea. They started to look at my legs and I think they decided that their skill was not … they couldn't do it and I was referred when I was two to Queen Mary's Hospital at Roehampton which I'm sure you've heard of.

I know it well!

I thought you might have done, because it's either going to be Charshalton or Roehampton, depending from this area isn't it? Well I was a Roehampton one, and I was put under the care of another name that you will know, Leon Gillis. And he struck up a very good rapport with my mother, and again, jumping forward slightly, I know he died in '67, but the last time that he met with my mother and with me, he actually said to her, "Things are going to happen about …" she told me this, "… about thalidomide, you need to make sure that Liz has what she's entitled to, it's not your fault." And I find that … she actually told me that, off her own …

I was going to say, given that you were going to Roehampton, and they had such a collection of Thalidomide children going there …

I know … when I first got in contact with Martin Johnson at the Thalidomide Trust, I mean I asked him about several of the Thalidomide children, I said, "What happened to … do you know?" And of course the trouble is, because I was a child, I couldn't remember many of the surnames. Some surnames came back to me, one in particular, a child that my mother had struck up a very good rapport with, and he was able to tell me something quite interesting because I could then … I said "Could you tell me quickly because my mother's very …" And that was quite … and because they were … it wasn't because they were thalidomide, that wasn't why she was interested, she was interested in them as people. She was very pleased to know that this person had done that … I didn't tell her that one person that she remembered had passed away, didn't tell her that, no point. And so that was quite interesting. From the age of two, until the age of nine I was under … no that's not right, from the age of ten, sorry, and in fact there was one … I did actually go once more after my tenth birthday to the Queen Mary's up at Roehampton, I mean that became quite a regular trip … and I subsequently discovered by sheer chance that what was known as the … lovely name the Children's Prosthetic Unit, lovely name … and I discovered it's now the Leon Gillis unit which I only found out, chance is a wonderful thing … a physio I was working with when I was teaching said, "Oh I trained at the Leon Gillis." I said "The where? The what? The where?" So that was lovely and she wondered why I then started to get a bit moist around the eyes. I said, "I'm terribly sorry, that genius gave me what I've got" because he then started humming and ha-ing and said "What should we do?" Well, he started on my legs.

Now I think … although the idea … because they were always obsessed with walking, it was an obsession that you were going to walk. What we learnt, this 'we' I mean is my mother and I, was that hands are more important than feet. Arms are more important … because looking at the ones who had lost either full sets of arms or legs, the ones who were more successful were the ones who had the arms because you can push a chair. Now I'm sorry, that sounds very crude, but we learnt that. And of course I saw all the gas filled cylinders and all the … I mean I've got very strong memories of all of those. I was very fortunate, none of that had to come my way, I was very lucky. Now when I was two, they did try me in … I had boots … they did try me … I mean why on earth they thought anyone could walk with legs bowed like that I don't

know, but anyway they said if you try … and there is an horrendous photograph of me trying which kind of shows how very uncomfortable and painful it was. Now the surgery started … the main bulk of my surgery happened between two and four and I spent the summer of 1964 plastered as it were, that sounds good doesn't it? I went to uni very early!

Especially at the age of two!

Yes, I was an early starter! And basically what I've got … now I don't actually … this hip was, I know was displaced, and I know that they put that right, and I have a scar there, that's when they put that hip straight, because that was why it was all around there, because it was displaced. This is the bit that children always love, when I taught they always loved this. I used to say "I've only got one knee." which is true, that's this one. I had a kneecap on this leg, but it's around the back, right?

Trying to picture that.

I know, it's amazing. And if it bent, I'd be like a flamingo. Children love that concept when … they love that. But of course they made that rigid and there is a massive scar that's caused a lot of problems actually in there because that was … they had to basically stick that leg together, that's how I put it, and then they had to make the ankle more rigid, because it wasn't. This leg, they had to make the ankle rigid, and also there's a scar down there because they had to put that knee into as good a nick as they could. But there was always an issue. Now my pelvis, instead of being like that, it's like that. So basically, not only is it … for the benefit of the tape what I'm saying is I'm putting my hands up to show that not only is it at an angle, it's at a skewed angle, right? So once they'd done the surgery when I was four, there were then photographs of me when I was going to school at five and we were trying boots again and it was a very unstable platform to walk from. I mean at this point, I'm not talking about any extra length, I had a built up boot because the right leg is shorter than the left, but I was at my height in boots.

So they weren't prosthetic legs as such?

No not yet, that's why I'm being very careful how I put this. And the major problem was this knee because it was bent. Now if you look, it's bent, it's flexed. Yes?

Yes, it's in a sort of permanent bent shape.

Well, I do not know what Leon Gillis had in mind, obviously. I think that he was further ahead than some and I suspect in his head, he may well have thought I wasn't going to walk because I wasn't … I hadn't … because they were learning the hips and pelvis … if you haven't got hips and pelvis that work, whatever you do, it ain't going to work chaps. They tried me on the classic rocker feet, and I just couldn't do it. I know I'm a relatively heavy weight now, although I've lost over half a stone recently, I'm working very hard, but then I was actually quite a light child, there wasn't much of me, and even then I couldn't do it so they gave up on that.

Now, Gillis died, sorry, Leon Gillis, I don't mean to be rude. He died in '67 … now I'm going to stop using names now for doctors because otherwise I could be done for slander … I was then put under the care of

another surgeon … what we would now probably call a paediatrician, but we didn't use that word then because we hadn't borrowed it from America. A child physician or whatever, and there they shared and obsession with walking and in 1968 they started to plan and plot, there is no other word for this I'm afraid, what would be the best way forward. And they decided that what needed to go was this foot. And they also decided that further surgery was needed on this knee which was entirely experimental, there is no question in my mind that it was entirely experimental. I mean, I'm sorry, but we're almost talking Mengele here, and in 1969 in the February I was operated on to straighten that knee. All I'm going to say is it took four months to revert back to the normal position, that is all I'm going to say, I needn't say any more need I? It's not a nice thought, and it wasn't.

Do you have actual memories of this happening?

Yes I do. I don't have any memories of what happened with the early surgery, I have no memories of that at all. I do have vague memories of … Leon Gillis I remember, I remember him, and that for me is quite extraordinary I'm not good on childhood memories, anyone will tell you that, I'm not good, I don't remember, but I do remember him, I do remember Sister Mears.

I was going to ask you if you remember Sister Mears, everybody raves about Sister Mears.

My mother and she got on very well and Sister Mears once said to my mother, made her a great compliment actually which I think was a very fair compliment because as you probably know by then, sadly, a lot of the more disabled children, thalidomide children, their parents were no longer able to cope, and a lot of them were in care, going to Chailey Heritage, I'm not calling that going into care, that was a school, but they were not having much more contact, that's what I mean. Sister Mears once said to my mother, "If you sat all the children in a row and asked which one was the one still at home, you'd pick Liz straight out". And I think that was true. So I think whatever else I've said, I was very grateful. Grateful's an awful word, but it will do, there was never any question that she wasn't going to have that.

And then they put me up … although the knee hadn't worked … onto prosthetic legs.

Did they take the foot?

No. Because … there you are, proof …my mother, and this is a true story, and this is why I've never mentioned any doctors names, I'm being very careful, was in the canteen at the hospital and, can you imagine what would happen now if this had happened? And there was a discussion going on the other side of a pillar between the doctor and the surgeon "Well then there's the Lash case" or words to that effect "Oh that mother, oh dear, what are we going to do? If we could just get that child's left foot off then we can do what we like." She heard them say that, you could say there's no proof, I totally believe that's what she said. And she came back, she didn't tell me, what she did, being my mother, was to get on to the aunt who I said had used to be a nurse and said "What do I do? Do you think this is … do you believe …" "Oh yes" she said calmly, "I do" because she was totally straight was my aunt, was Ann, totally straight "Yes dear, I totally believe …" But she said "Don't take her away immediately … whatever that foot, just keep …" So my mother kept a very close watching brief. She said to me, when I was a lot older, "I started then to listen so much more to you, what you wanted, because you were bright, and you knew." Well, I still hadn't got a wheelchair by this point.

So how did you … were you being carried around or did you have a pushchair?

I was being carried or there was an adapted pushchair. My mother went to the local secondary school and they built me my first wheelchair. One slight thing they forgot though were brakes, a problem, but never mind, it's true. So my mother then started pushing, pardon the pun, saying "I want a wheelchair, she needs a wheelchair" and the first one they provided was so heavy she couldn't lift it in and out of the boot of the car. When I was … I was what they would now say was year five, I have to think, you have to do the maths. They were going to put me up on to the prosthetic legs so I was going to be the right height for my age which apparently they can work out to do with your vertebrae and various other things and I would have been very tall so I shot up and I was taller than anyone else in my class. I don't think that was very clever myself, apart form anything else, and I spent six months, there or thereabouts, not walking on prosthetic legs.

So you had the legs on but you sat …

I hated it. I tried. They tried on shorter ones and they said "Oh yes that's all right" and I thought "Oh my …" and in the end, I can remember doing this, I was then about ten and a half, I said, "Am I ever going to be able to walk without needing a wheelchair? Am I ever going to walk very far?" "Oh yes," I said, "No, I want an answer." Of course the answer was I'd always … I said "All right, okay, fine. I don't want to bother." I said, "I want a life, I don't want to be …" and by that time I was starting to get an interest in the theatre, that was my passion, and I was ten. I was precocious enough to say I was going to be the first Shakespearean actress in a wheelchair, but there you go. It's a bit sad isn't it? And I was also finding another great theatrical passion of my life which was dance, which may sound slightly odd but it was an absolute thing of mine, still is. But I wanted to live and my mother said "Are you sure?" She said, "Are you absolutely sure about this?" and I said, "Yes." So they all threw up their hands in horror, but she withdrew me from treatment at Roehampton, transferred me down here and said to the GP "Can we get a wheelchair?" "Yes." I mean, nowadays we'd know, but we didn't then.

Now, one thing that when we came to look through my notes, we did go back the following year, in the August before I went to secondary school and I have no recollection of that whatsoever, I remember all this stopping, but I think they must have said "Come back" and I went back in the Barrett chair I had then and I was coping fine, and about to go to secondary school, and I think they realised I was a closed book, I wasn't going to be any, you know? And that is when I saw somebody who'd been a houseman to Leon Gillis and who actually wrote on my notes that I was Thalidomide. And when I subsequently saw Doctor Newman he said he was also a houseman of his and he said he's done that on purpose hoping that this was going to happen at a later date. He said "That's intentional." It is extraordinary! But complex!

You know that your mum would have probably had conversations with the doctors about you being Thalidomide?

I don't know, I don't know. Martin Johnson from the Thalidomide Trust said to me "Did she talk to Leon Gillis about it?" I said, "The only thing I know about, is what she told me, that Leon Gillis said to her." I said, "I don't know anything else." I said, "I don't think that much was said." I said "My mother blinded herself, it's the only word I can use, she's not thalidomide." And like you said, the lie becomes easier, you build it up over the years and it becomes the truth, and it's become my truth.

Yes, it makes total sense, but do you think that some of the reason why she didn't tell you would have been because of that maternal guilt that so many mothers felt because they swallowed the tablets unknowingly but … ?

Yes, and the guilt must have only been almost compounded by what was going on in her own life. The fact that my … my grandmother was a lapsed, and then went back, Catholic so she knew how to do guilt and she was very good at passing that onto my mother, so she was always guilty about everything anyway, so if you compound that then yes, I totally agree.

You can understand where she came from can't you?

Sort of. Yes yes. I actually had a year's worth of counselling after all this occurred because I just couldn't handle it at all. And I couldn't handle what it had done to my relationship with my mother, that was what I couldn't handle. So yes, I'm in a place now, that sounds like a bad book, but yes.

Was it the fact … the thing you couldn't handle … was it the fact that she lied? …

That she lied. There were two things – the fact that she'd lied, because I have a thing about truth, if you like. But also the fact that she had been unable to see how much it would have been so useful, purely on a practical level. I don't mean a greed level, but because financially we weren't that well off, for various reasons, because we weren't, so it would have been useful, it would have made such a difference. And I thought, "Why could you not see?" And I did say that to her and she hadn't and I said "You must have known, it was everywhere in the papers." and I said, "surely people were saying things to you?" And she did actually say, "Yes" and I spoke subsequently to two of her closest friends, on the advice of the counsellor actually, after my mother had died. And they both said, "Well yes, we said it. We said it and she wouldn't budge."

It's extraordinary isn't it?

So that was what I had problems with. It's very strange, but I think it was also part … there was also the fact that she was … her life was my life, and I think she was so frightened that that would have given me more freedom in a way. I don't think she knew that she thought that, I don't mean that was a sort of … it's ever so complicated.

So after you'd been born, you moved in with your grandparents and do you think that that was the point that your mother, in your words, became quite obsessed with you and built her life around you from then on?

Yes basically she did, yes. She taught part-time at what is now Sussex Downs College, it went through various names, she taught English. And it was a good job she did because that was her only other outlet really and a few and close friends … she's the opposite to me really … she wasn't a social being at all. She had quite severe mental health issues of her own in fact.

Would you describe yourself as having had a good relationship with her though at that time? A close bond?

Oh yes, very much so. It got a little difficult when I got older, but yes very much so. And it was very much a supportive thing because my grandmother subsequently got vascular dementia and that got very difficult as these things do and nobody talked about it in the way they do now, thank goodness they do. And so it was all very … I mean she had a very difficult life and I'd be the first to put my hand up to that, but it needn't have been quite so difficult.

I suppose what's hard to square up is the fact that she was being given a lot of advice from other people, but still somehow in her mind she was making that …

People she trusted too. But I can now accept it, thanks to the counsellor that I went to who was very good, but it took a long time, it wasn't a five-minute job. It's one of the things that the government grant helped to pay for is the counselling which is a bit ironic when you think about it - I had to have a health grant to help me accept the health grant in a sense!

Okay, a lot of these questions you've naturally covered. And questions like at what age did you know your impairment was caused by thalidomide well …

Forty-nine!

I think that's got to be a first for me! And you've talked about when you got your compensation through. So your parents wouldn't have attended any events organised by the Thalidomide Society.

No. My mother knew of their existence, I do know that, but no.

And did you ever encounter any other thalidomide children, say at school or …

Well in a way, not at school directly. I went to school with Alice Yendell. She was in my year, and of course her brother was Tom. She wasn't a close friend but I knew her and I knew Tom, and I subsequently got to know his parents and they said to Tom "Well she must be. Why does she never turn up at anything? What's her surname?" sort of thing. Not inquisitively, just puzzled. And apart from the ones I knew at hospital, Christopher, and Tina … you see I can remember the names. We watched with great interest *On Giant's Shoulders* and all that sort of thing because we knew Terry when he was Andy so, you know. And my mother remembered him very much shinning up the curtains in the room and my mother lifting him down. It's true, that's what she remembered. And she could talk about that with me, and she could talk about those times without any problem at all because she was talking about them as people, not about thalidomide children. Does that make sense?

Yes of course, yes. So she's not having to talk about something she's avoiding.

No, that's right.

And do you have any anecdotes about that time at Roehampton?

Not really, no. I don't … I do remember one thing and I can remember who said it to me and I was then about five I suppose. And the girl who said it, one of the girls I'd got friendly with, definitely Thalidomide, she was one of the ones whose impairment unfortunately affected all four limbs and she said to me "You know you live at home and your mother comes to see you," she said, "You do know, don't you, that one day she won't come back for you?" And she wasn't being unkind at all. She was about six months older than I was. She was preparing me. And I was so sure of my mother, I told her, and I remember doing that, and I remember saying to her, "Isn't that awful? That's what she thinks?" because I knew she wouldn't do it. So I was grounded and sure that I knew that wouldn't happen. And I can remember being … but I was, it sounds terribly precocious, but I was so sure of my own ground, that I understood why she had said it. I wasn't angry, a lot children would have been.

It was just her experience wasn't it?

Yes. And I said to my mum, "It was nice of her to say it though wasn't it? She was trying to be helpful."

Now I remember funny things over night, some of the other children, because that was the first time I came across children with spina bifida and the beginnings of understanding … because one mother had two children with spina bifida and then she got pregnant again. And I can remember hazily that was the beginning of my first awakening and I said to my mother, "Does she know that she might have … I said surely if she's had two …" I mean even though I was only eight or nine it seemed … I was a bit older then … it seemed to me logical. And she said, "I don't know." and I said "That doesn't make sense." And I can remember, isn't it funny how you remember? And it was almost the beginning of my own awakening. And I remember my mother being angry with the woman who said that she wanted a normal child to prove her own womanhood, and I remember my mother really laying into her and saying, "It's not about you, it's about the children." My mother was a very, very quiet woman, but if you touched a raw nerve, you knew.

Probably in defence of you …

Absolutely. She used to say her tigers got out. I remember very clearly having had the operation on my knee and I remembered when they were looking at the wound, and I remembered the leg being straight and it was almost as long as the left one then, and I remember thinking to myself, "It's not going to stay like that. I'm sure it isn't, whatever they've done." But I never actually knew what they did. I never knew what they did. And I can remember thinking as a child, "I wish they'd tell me what they're doing." That I do remember. Not voicing it, children are funny.

They are.

But the tremendous relief. And I'm a great, what's the word? Go through a door and shut it behind me. I didn't need to think about it. Not because I hated it, because that was over.

I think that's probably a very good way to be.

My mother said it was like my father. I'd inherited it, she was convinced of it. If that's genetic I don't know. But I've got very few childhood memories. I remember a lot of … we went to Canada in 1965 … I remember a lot about that. And I remember various things in my life that tend to be about particular individuals and animals which will make your daughter smile I'm sure. But actual memories, no. If you said to me "Do you remember certain things at school?" I'd probably say "No." I know they happened, but remember them? No. Not the same thing.

That's interesting. So, school. You said your mum did all the right things in terms of getting you into a mainstream school, not a special school.

What she did was to … this person's passed away now … but her then boss was a married man with whom she was having an affair. She had an affair for over twenty years, I think it kept her sane to be honest. She said it went on for so long, it was almost acceptable. She knew he knew a lot about the rules and regulations and she said "Right, what's the situation?" So he went away and found out. He was a great left-wing activist, very useful. He was a strong South Wales left-wing type, very useful. I think it helped her to understand my political views when I got older. And he discovered at the time that if a school would accept a child, the local authority couldn't say no. Now that's the law back in 1965, it's not the law now, but it was then. So my mother briskly went down to our local primary school and explained and they said "Well bring her down, let's have a look. Yes, we can manage." And I went into Miss Law's class and I went to Pevensey and Westham Church of England Primary School. I had somebody to help take me to the loo because this is way ahead of the days of accessible toilets, obviously this is a long time ago. And those two people actually ended up being people I still know. One of whom is still living in Westham Village and I'll still see at the Women's Institute and things like that, because I've still got connections with Westham.

And then when I was nine, the local authority started nosing around and thinking to themselves, "Hmm, we've got quite a bright one here." So they sent an educational psychologist along to the school to test me, not telling my mother. And I was duly tested. And I subsequently sorted out, because of my knowledge of schools, that they wrote to my mother that I'd been offered a place at Treloar … I had to work out what the school was because she couldn't remember, I worked this one out. My mother went just a little bit in off the deep end, charging in to the then head teacher who I almost felt sorry for, nice man, but couldn't stand up to my mother in that kind of thing. First of all "Why haven't you told me she's been tested? She's not going away to a special school …" Off she went. Now this is in the days of the Eleven Plus and because Eastbourne in its strange way was a unitary authority, we're not talking about Eastbourne schools, they're out of it. It was, if you passed your Eleven Plus, you went to Bexhill Grammar School in Westham. If you didn't, you went to Willingdon Secondary School, a secondary modern. This is of course long before the days of choice and whatever. Now my mother duly contacted Bexhill Grammar School which had only just become co-educational, that would have been another problem, because my mother was determined I was going to a co-educational school, mainly because a lot of my friends were boys, because I didn't really like girls, and I didn't like girly things, I wasn't a girl. Well I was, but I wasn't into girl things. And she went along to see the then deputy head, who'd been the head of the girls school, a woman who passed away about three years ago with the wonderful name of Miss Copshoot. An amazing lady who interviewed me, who said "Bring her along to see me." And I also met the then Head. And they said "Well, it won't be easy, but yes of course, if you pass the Eleven Plus, she'll come here."

Well, Willingdon Secondary School definitely wasn't accessible, steps and stairs everywhere. I've subsequently been there and it's not. My mother had taught there so she knew the Head, whose name escapes me. But she went to see him and he said, "Well I doubt she is coming here, but if she does, we'll manage." Sorry, but that's what he said. Well I passed the Eleven Plus and I went to Bexhill Grammar School, basically.

That had its moments. From an academic point of view, there were mistakes made, but that was nothing to do with my disability is how I'd put it. They had me down as Oxbridge. That was the problem, they'd got it into their head, but that was never me. So some of the directions they … I was bullied, but again, it was nothing to do with my disability. I was bullied because I was a good girl who did my homework. So I had to be swapped classes in the first year because of that.

Did you encounter any kind of disability prejudice or that type of behaviour at school?

I did, but I just dealt with it. Usually with a very sharp tongue. In my primary school, I knocked a boy over. I was so angry with something he said, that I … it's funny when I think about it … I caught him off balance obviously, because me in my wheelchair, I'm not going to be likely to knock a boy over, and he landed on the concrete playground, and that kind of put a stop to it. But it was just a lucky, or unlucky, depending on how you look at it, punch.

Not much though. Secondary school, yes there were difficulties, but more from the staff, I have to say. I've always said, I made some very, very good and strong friendships, I've still got very strong friendships from my secondary school. I'm friends with someone I met on my first day going to primary school. Diane and I are still close friends, and that's a very strong bond, we've been through a lot together with one thing and another. And her family were a nice normal family for me to have as … to escape to every now and again. That sounds a bit awful but, you know. Even though she had a sister with a lot of issues of her own, it was still to me … she had aunts and uncles that came to visit, and cousins and ordinary grandparents, it was quite a shock to my system. But friendships that were more important yes there were … and I think there were some people in the secondary school who probably did resent me, but because it was a grammar school, it was slightly different. I've always put my … and I will always say this … I wish I'd been to a comprehensive, not a grammar school. I don't like elitism, and I don't like the other side, the, as my mother said, "I'm a failure at eleven." I like inclusive education so that was the system, it wasn't my choice.

I still remember, three days after the results came out, a lad who'd been a good friend of mine, meeting me, meeting us out and about and saying "Are you still going to talk to me now you're going to the grammar school?" And I was eleven, that hit hard. That really made me think. And I can remember coming home and saying to my mum "Something's wrong," and my grandmother helpfully saying, "It just means you're cleverer" and I said "No, no, this isn't right." I said, "Do all countries do this?" being me. I was always a bit odd about things. The first time I went to a wedding when I was five, this is a memory I do have. I said to my mother, "So when does the man take the woman's name then?" And she knew then at that point that she had somebody very different, which is absolutely true, but I couldn't work it out. "What? Excuse me? Why does the woman have to take the man's name?" I wasn't having that! I was very … my mother brought me up to be very open and very accepting. Although in some ways it was a traditional Church of England upbringing … I mean another thing that happened when I was six, when my uncle was over from Canada. He was so straight laced, bless him, his backbone wouldn't bend at any time. And for some reason, I don't know why, the word homosexual was mentioned, and I said to my mother, because all words were like that me at that age, I said, "What does homosexual mean mummy?" And my mother said, "It's a bit difficult, I'll tell you later." So fine. So appalled, when I was not in the room my uncle said, "What are you going to tell her?" To which my mother calmly said, "The truth." "You can't say that!" "Of course I can!" "Well maybe she won't …" "Of course she will, and I will tell her the truth." And that's what she did because

that's what she … it was an unbiased, unprejudiced, because my mother wasn't prejudiced anyway, truth. And I was brought up to accept that some people were gay, some people were straight. And that was years ahead of her time. Years ahead with things like that. And yet, if anybody had suggested that I might go to a club for disabled people where I might have been able to access the one thing I think I did miss out on, because it's very close to my heart, is disability sport – Oh no!

That was her big fear. I started getting a bit involved. It was fine when I was involved politically when I was at uni and stuff because it was nothing to do with disability. I've always said I've marched for things twice in my life, and they weren't for disability. I'm showing my age now, the ending of the GLC in London, sorry Ken, but we did try. And also for gay rights. And those are the two things, nothing to do with disability. Which always makes me laugh when I think about it.

So basically all of your life, up to this point in time, you didn't have any contact with other disabled people at all.

No, not at all.

So your whole life was with able bodied people?

Yes, I mean I did a lot of drama, music, that sort of thing. Went to the theatre a lot. Once I'd found that I was … and dance was the thing. Performance was what I liked watching and being part of. We didn't have drama schools for children, it was really quite basic stuff. My mum and I used to do the Eastbourne Arts Festival and sing. I sadly still remember the songs and things, it's a bit sad really, but there you go. And those were the main things that I did. And I certainly had a very full social life with my friends. And I did some schoolwork I suppose … I mean I did. A book – my nose was always in a book.

So your main aspirational subjects when you were at school were all to do with art and drama?

Yes. Because of my interest in animals, I had a bit of an interest in science. Because my mother put the books of Gerald Durrell into my hands, who was the one who started my passion, he lit the fire that never went out. And I got to the Durrells who were in Jersey for the first time only three years after he died which was a great sorrow to me because I would have loved to have met him, he was my hero. I've always said I cried when two, in inverted commas, 'celebrities' died, and he was one. I know it sounds silly but there you go.

So I had got an interest in science, but academically, it was always arts – it was English, it was History, and Politics. That was the other thing.

That's an interesting sort of round the corner one isn't it?

Yes. I developed an absolute fascination for American politics after the Watergate scandal. I was absolutely fascinated. I had any book that my mother could … she was very good at sourcing books on the most peculiar things … I mean I was fourteen and reading things like John Dean's autobiography, I really was a very strange youngster. And I was just absolutely fascinated by anything like that. Anything to do

with what people said, and spin doctoring … I mean I now say that I wish I had gone a studied politics at uni.

We're now into the second part really, which is looking more towards early adulthood. First question is what were your feelings about your impairment around that time, say when you were in your late teens?

I don't think I had any feelings about it. I think I'm meant to say, in inverted commas, "Oh it had tremendous effects during puberty and to do with boys …" It didn't. I did have some issues when I was fifteen-ish or so about that fact that I couldn't go and do things that some of my friends were doing.

Like what? Can you remember any of these?

Yes I can. It was partly because my school was in Bexhill and if people were going off to meet after school, that wasn't going to work from a transport point of view, and things like that. That was a bit of an issue. And then when I got a bit older, sixteen, seventeen, it was a case of finding an alternative. And so my mother talked to her students because she was teaching seventeen year olds. They used to stream the English O Level students that came to the college having not passed at secondary school into five sets and she had the bottom lot, because she was good with … and she talked to them about me and said, "What can I do?" And they said, "Well, are you against her going to a bar?" "No," says my mother calmly being totally unmoved by anything like that! Now this is long before we have clubbing or anything else. And so I was introduced to something which was called, of all things, the Hunting Lodge Bar along the seafront, to which my mother would quite happily take me, leave me, and come back. And I would initially meet a couple of her students.

So what happened was, I went in once … because she had a group and she said to me "Liz, I don't know what I'm going to do with them. I can't get them excited about anything or interested. Would you mind coming in and talking to them about your life because I think you might bring a bit of a spark?" So I did. And one of them I really fancied – cor!! But that was no good was it? And so, it sounds a funny way to get a social life doesn't it?

Well, yes and no …

But it worked.

Yes I think that's the most important thing.

But it was a bit of an issue. I hadn't had … I didn't have … I wasn't ready for proper relationships. Part of it was because I was also in, what I call, looking back, my evangelical mode. I was very much a leading light of the Christian Union at this point at school. And I'm not saying there was anything wrong with that, but it meant that boys didn't figure in that way. And also, we didn't grow up that fast in grammar school, because you don't. I had lots of friends that were blokes, you know, boys. I'm afraid at the time I had a passion for fast cars. We won't go there. Other people had pop stars on the wall, I had Ferraris. I did tell you I was strange! And football, which was an abiding passion.

I don't get that one.

No, neither does my other half. In this house, I'm the sports person and he likes chocolate, we're reverse … it's true! So I didn't actually think about my disability as being a barrier. I think without knowing it, I'd got the social model without knowing I had, because I would have seen that the transport was the issue, the step was the problem, not my disability. That's how I'd put it. Without knowing it, that's what I was thinking. What I was thinking, I'm saying now, not what my mother was thinking, but what I was. Because I think there's a difference. We are getting a slight split now and I started to see things slightly differently.

Yes. So when did you actually leave home?

That was quite some time … well I had a bit of a, ahem, a bit of a muddle with my A-Levels. A right to-do that was. In 1978 I took, you won't be surprised to know, English, History and Political Studies, and one of my English lecturers, tutors, whatever, tutor is probably a better word, the indomitable Miss Taylor, you didn't argue with Miss Taylor, lovely lady. She went in to see if Liz had got her A. Liz had got an O.

Oh dear.

Liz also had an O in her History.

Oh dear.

And only an E in her Political Studies. Mainly because, the big problem was the silence in the exam room. I don't handle silence, I don't like it. And so I had got a place at teacher training college in London, and to pardon the expression, all hell then broke loose. Part of the problem was me saying, "I'm not going back to school. I've done that, I won't go back."

Getting a bit strong willed then at that point.

My mother said, "Okay then, fine." So I needed two A-levels, that's what I needed. That's a bit sad, but there you go, and what I did from September '79, to the June of the following year, '78 I mean, I went to the college where my mother was teaching and I did another two year English A-level course in a year, with a friend of my mother's. And she said to my mother "How on earth did she manage to fail?" And I did very little work, did two years' work in one year, and I got a C. Because during that time I got a car and learnt to drive, and so freedom awaited and that was a little bit more interesting I'm afraid.

So you saw the light at the end of the tunnel? There was a purpose for getting the A levels.

Yes, exactly. I hadn't done very well in my O-Levels for the same reason … there were other issues going on there at the same time to do with my grandmother that didn't help, but I freely admit that I wasn't … I

mean I didn't study as well as I should for my A levels to some extent. I liked reading what I wanted to read, that was part of the trouble.

And at that point you were still living with your grandparents and your mum?

No, by that time my grandmother was in a nursing home, because she was no longer able to cope. So it was my mother and myself. But then I went in the September of '79, so a year late, but actually I think that was a good thing because by then I was driving, I'd got confidence. So I always say to youngsters … I hate the pressure we put on our young people, I've got very strong feelings about it, and they all fool about, and their A levels go wrong. My partner's nephew, there are some issues with something and I'm thinking, "Woah, he's seventeen, just back off! It's not the end of the world." I proved it. And then I did my A-levels. I had a great time up at the college. I became a PR for a local rock band for year, great fun.

How fantastic!

You never know what I'm going to do next! And then I went up to college … to uni, teaching training college … and I'm glad … I mean I made some great friends that year. People I probably wouldn't have met. So that was when I first encountered prejudice, going up there. Having fought my way in. I regret to say, and this is something I'm not sure I want to say on record but I will because I'm awfully sorry to admit, that I learned to teach what was called, I'm sorry about this, mentally handicapped children, I'm terribly sorry, but it's what the course was called. It breaks my heart to say it, but it was the terminology. But to cheer us all up, can I say that the course leader, who was wonderful, was called Bob Battey, so it's not all bad! I knew when I saw the prospectus …

How come all your teachers have got strange names?

And the Head of Music? At Avery Hill College who I was to get to know very well, was a Dr Fiddler.

Oh perfect!

Honestly, I'm not making this up. And there was a Mrs Y Singh, but sadly she wasn't in the Music Department. And there was also a Mrs Hands in the Movement Studies.

It's not quite as good as the Dr Deth who I came across who was a surgeon …

Yes we had one in Eastbourne who was a dentist! It's pretty good! I love it. It's great, you just, "Yes!" I'm sad, I love funny names.

My daughter's headmaster is Mr Hayter.

Oh that's good. Of course my name is pretty good for a teacher.

Your name's quite cool actually.

I would never get rid of it. But if you run my first two names, you get Miss Slash, the boys used to call me that once, but not twice.

You could get fed up with that couldn't you?

And I used to say "Yes, ha ha, not again." "All right, okay Miss".

And so you left home to study to be a teacher in London …

I did.

How did your mum feel about you leaving home?

She said she was going to run a flag up a flagpole because that was what we'd always wanted.

So she'd sort of broken that little bubble of being obsessed with you do you think?

She was thrilled to bits. No I don't think that because … no. I had a lot of prejudice, not from the people on the course, but there was some practical stuff they didn't quite get what they needed to get right. When I look back on it, we're talking late seventies, early eighties, it was even pre the International Year of Disabled people in '86, and people didn't do things like that in those days. Nowadays it's a very different world, I'm pleased to say.

I've left out one bit that I ought to have mentioned that before I went to college I did seriously … what I really wanted to do, I mentioned dance, I wanted to be a choreographer. And my mother and I did actually visit the Institute of Choreology. And I considered learning the Banff notation for choreography. And I also got to know some young people touring in a production of Godspell at the time, it was a very long time ago. And I watched them work … there was for some time actually a bit of dance in the production of Godspell that I'd done going around, and I eventually realised that it wasn't practical. I'm delighted to say that now it would be with things like Candoco and all the rest of it.

Why would it not have been practical then?

It just wasn't going to happen. And I thought "Ok" I'd been going form school on a Friday to the local school, and I'd really enjoyed that. And the head teacher there, a guy called Leslie Hurren said to me "You really ought to go into this Liz. You are very, very good. This is where you ought to …" And so that was …

but second choice is … I did drama as a subsidiary, the drama was still there when I was at uni, and I still did the music and whatever, I didn't stop. But I had to take a more … I'd always said I was never going to teach, "Oh god, both my parents were teachers I'm never going to do that." But I always said I wasn't going to teach all of my career, that was always my cry. "Okay I'll do it to start with" and that was of course what I did. So … yes there were some issues when I was at uni. There was one lecturer who informed me that the people, he wasn't on my course, but he told me that the people who I'd been at school with would have been psychologically damaged because they would have been in the same … taught in the same way as me.

No way!

Yes.

How? Why?

Well the context was that we were in that room for … our group was in that room for something and he came out … I have to be very careful how I put this, I don't suppose anyone would ever find out who it was but you have to be careful … and one of the other members of the group was talking about something else and he looked at me and he said, "Oh, are you visiting?" so I said "I'm in this group. What do you mean am I visiting?" I was just puzzled. And he said, "Oh are you training to teach?" in tones of absolute blank bewilderment so I said "Yes," and he said, "So you're going to teach in a special school?" and I said "I don't know", well I didn't, you know? And he said, "What school did you go to?" so I told him, and he said "Were you the only wheelchair user?" I mean I don't know term he used, I'm using 'wheelchair user', I expect he said something like the only 'wheelchair bound' or something, but I don't know what he said. And I said, "Yes, we had a teacher who was because he had Multiple Sclerosis" and that's when he said, and of course all of the teachers just laughed and so one of my particular friends said, "When I don't pass my degree then I'll blame you."

And he did not expect the support I got I don't think. It was a long time ago, very strange that was. Very odd.

Very odd indeed. And how did you feel about leaving home and moving away, going off in your car, in your Ferrari!

A Mini! I was a student, it was a Mini! SPP 107R, how sad! Excited. Okay it was a bit scary, of course it was.

What sort of accommodation were you in?

I was in hall. Because in those days a lot more people were in hall than they are now. I didn't have that … I think it's a very different situation now. And that was fine. We went across to have meals in the canteen so we didn't have to do a lot of … the kitchen was upstairs so that was a bit awkward for milk for coffee and things but you know, I had good friends.

Did you have any help? Did they make any changes to any of the buildings or the facilities?

No nothing. They changed … they put a lower bath in, eventually. And knocked a wall down between the bathroom and the toilet, and some people complained about that and so some other people in the same … and so the hall was arranged so you had, like, I'm trying to remember, there were four or five rooms … I can't remember which now. No, there were five. One, two, three, four, five. And then there was another four upstairs because there was the kitchen and there was a bathroom on each floor. And when I first moved in somebody said something about the bathroom not being right and so the other people on the floor said, "Right, well, we'll get rid of her, can we have someone else in?" And that was before they even knew me very well. And they did quite well on hand-picking the students because they picked a mature student which was a clever idea. I didn't actually get on with her that well but I thought their theory was quite good. And two others who became very good friends. And so … they didn't pick people on my course. There was one person on my course who subsequently again became a very good friend but it would have been very good to surround me … whoever picked, that was clever. In fact, I ended up, again, with friends from other courses not just on the teaching course. PE students I tended to lean towards. I don't know why, I can't think why. I was always a rebel.

And any health concerns or medical interventions at this time?

I was fairly … I was okay. I mean I had … the sinus problems were showing up by then. I mean I've worn glasses since I was ten. But generally speaking I was pretty healthy. And there weren't any other … I mean I was fairly strong. I swam a lot when I was a youngster, a lot. And I went on swimming when I was at college. The joke was, "If Liz hasn't gone home for the weekend but her car's missing and it's a Saturday, she's probably at the swimming pool." I was ploughing up and down.

Did you often go home for weekends?

I used to go home third or fourth weekend.

So you really did sever the ties in a way.

Yes I did. I mean I was involved in things up there. I was lucky in that I had some friends of my mother's who I could go to as well. I developed a very strong bond with my father's brother's closest friend before he'd gone to Canada and their family happened to live just down the road from uni really and I did develop strong bonds there and that was nice and if ever I wanted a bit of home comfort they were always accessible.

Did your mum come to visit you?

No, by then she wasn't … she came once and everyone made a great fuss of her which was nice. But she didn't like driving long distances and by then she came up on the train. I should explain I used to say my mother was like fine wine, she didn't travel well. She didn't like going far from home, she really didn't. So, you know.

And teacher training, you did that at university.

Yes.

And did you do any follow up?

No.

So you went straight from university into teaching?

Yes, yes.

And what was your first job?

This is where it gets really difficult. I mean I actually finished in the November of … let me think, I always get my years muddled, let me concentrate. I should have come out … it was November 1982 because I had to go back and re-do my final teaching practise because the school they put me in they weren't able to cope from an access point of view. It wasn't the school's fault, it was the college's fault and I withdrew myself and caused a right deal of fuss. They said, "You can't do that." I said, "Well, I've done it."

I said, "I'm not going to fail, I won't." I said, "Why should I fail because you put me in the wrong school?" So then they put me in a wonderful school in the middle of Peckham, absolutely wonderful. We had a wonderful Head who was an amazing woman and having been told in my second teaching practice by the Head there , which was a junior school that, "Are you sure you're not going to stay in London? Please apply for a job if you do" … a very quick anecdote, it happened to coincide with the parents' evening but of course students don't see parents but one particular boy's father had said could he please come and see because Danny had talked so much about Miss Lash because I had used sport a lot to get them interested and to get them going with some stuff. And Danny had made some strides. This very handsome man walked into the classroom and I thought, "Wa-hay" because I can see him now. And I said, "Yes?" He said, "Excuse me, are you Miss Lash?" and I thought, well, I can't be anyone else really can I? "Yes, that's right, I am. Are you Danny's father?" I said, "What is it?" I'm welling up now remembering it. He said, "I'm so proud of my son." I said, "Yes?" He said, "He's talked about the football and they way you've … he's talked about how when he had to be … you had to keep him in, you have to explain very carefully. You know what he hasn't talked about once?"

I don't want to go to school?

"You know that Miss Lash, she's in a wheelchair." And I just looked at him and I said, "Oh!" He said, "It's not important to him," he said, "You've done something right then haven't you?" I can still … where are we going with this? Oh, is that you …

So when I left, that was the November, and I came home, contacted the East Sussex County Council because by then, in those days, what you did was you applied for the pool if you were an NQT and it was wrong for me because it was all messed up and I was just batted and batted. Eventually I got through and I said, "You're happy to pay for me to go off to be trained but I'm not going to get a job." Well, now I don't want to say too much about the first job I had because I had a huge guilt about this, I was very young, I was very green, I should have reported the school but I didn't. And I'd rather leave it at that. It was not a state school. I saw things that were wrong. I got the job because somebody knew the Head. It was a special school, I don't want to say what sort of school it was because it would be wrong. And I started there in the January and I eventually realised that in the … where am I? I left in the July of 2004 because … rather than leaving I should have done something.

Without naming the school, was it …

It was a special school but it was not within the state system. Some of the children who went there were funded by a local authority. It is no longer around I'm very pleased to say, but there were practises which were not good as, you know, it wasn't …

Upsetting.

Yes. But, as I say, I should have done more than I did. But I'm afraid when you're young you tend to think very much … I'm sure I was thinking it was the beginning of my career but what I saw was not right.

I think it's quite hard to rock the boat of an institution when you're very young. You think …

How do I do it? What do I do? If I had spoken about some of the things that I'd seen to my mother, I don't have any doubt that the roof would have come off that place because she would have supported me. I didn't say anything. It was years before I said something to anyone about why I left. There were other reasons why.

Then I had a year out of work then I discovered that East Sussex County Council were definitely not going to employ me, they were blocking it in all areas.

Did they give you a reason why?

Oh, lots of reasons. "Well, that particular school you've applied for doesn't have access, there isn't an accessible toilet and there's no parking, we can't guarantee your safety." I had that from a school with youngsters with behavioural problems.

What did you do?

Well, that year … eventually I went into a local primary school to do some drama, get some more experience and stuff, which was great.

Was that on a voluntary basis?

Yes, it was voluntary. And I did a couple of history courses so that my brain didn't die and sort of kept on looking. And then eventually in the December of 2005 … no, that's not right, 2006 … that was 2005 when I left the previous school, eventually in September 2006 I landed a job in St Mary's School in Westwood Road in Bexhill which is a school that is … all children who go there are funded by the state. It is a specialist school for children with communication and autism and all sorts of other issues. When I went there it was struggling but then a new Head came in and it is now … by the time I left in October '97, it was already becoming … it's now a centre of … in that place I grew as a teacher and I developed my interest in autism. I'm proud to say that for some time I was a member of the SAS. I love saying that – Sussex Autistic Society. And I also started to get a good understanding of parents because I got very involved with them and I was allowed to sign … [phone rings].

Shall we pause for a while?

[Break in audio]

Right.

Okay, so Liz, how long were you at St Mary's?

Well, I started, when I eventually got my years right, in September 1986 and I was there until October 1997. And during that time, hindsight being a wonderful thing, issues with disability started to affect me when I was there. I started to develop issues with my wrist which I subsequently discovered was carpal tunnel which I discovered when I started to develop issues with writing and things which caused me some issues delivering reports and stuff. Nothing much but I didn't see it at the time. I didn't have any issues as a disabled person there, that wasn't … I had a lot of relationship difficulties and, as a result of that, thought I was going to move to Manchester and I also wanted to stop teaching and do something else. I needed a change of direction in my life because I'd had … I had a broken relationship come to an end and I needed a massive change. I left in the October because I was ill, I had a stomach ulcer bleed which was as a result of my having taken pain killers for my knee which developed severe arthritic problems. It was in the days before they knew that if you took a high dosage of particular pain killers, you would have stomach problems. I was taking something with a wonderful name – Brufen Retard, which is a great name, isn't it? Great. And that caused a stomach ulcer which bled and I had to be transferred to hospital rather fast for a blood transfusion.

Gosh.

It was all a bit dramatic.

Very dramatic.

The doctor came to see me at home and, of course, I thought he'd gone mad because he said … I had an ear infection because I said I didn't want to drive because it wasn't sensible. At that point I had moved and I was living in Pevensey on my own and I said, "I don't think I ought to drive." And he came to see me and he said, "Are you wearing very silvery pale pink lip gloss?" And I thought, "What is the matter with the man?" I was so pale.

You got very anaemic.

Yes. Yes.

You mentioned earlier and we didn't go back to it – you said later on in life you had some internal problems that were caused by thalidomide …

This is not then, this is later. I had … well, it came to light when I first started teaching at St Mary's. I got irritable bowel syndrome which … I didn't know what it was, I was very lucky to have a good GP who is brilliant at diagnosis, he's retiring at the end of March and it probably is another impairment-related one because a lot of us have got it, as it were, and the way … the symptoms I've got do relate to that. And that has caused some issues with, you know, with diet and stuff basically.

It would make sense for it to be linked in some ways because some babies were born without an anus, weren't they?

Yes indeed. I was very fortunate that all my tract bits were in the right place and gynaecologically I was very fortunate because I had all that checked out when I was in my early twenties. I had that checked out because I just wanted to know whether I could carry a baby or not. I thought it would be sensible to find out, I've got this terribly practical mind, you see. The doctor said, "Yes, that seems sensible to me." Because I'd always had very heavy periods and I was put on the pill when I was sixteen because of it and the doctor thought it was very sensible that I went along and that's when I was told, "No, no, everything's in place." You probably wouldn't be able to give birth naturally in all probability although you can't be sure. But you certainly could carry. But I wanted to know.

But I was, as a child, I had what was termed acidosis which, again, you see it's very difficult. With hindsight it may well have been linked and in the Christmas of 1964 I nearly died from it because I became so dehydrated and the hospital didn't pick up on how ill I was. Not … to confuse the issue, not Queen Mary's at Roehampton, I'm talking about St Mary's in Eastbourne, just to make life more complicated.

There's a lot of Mary's, aren't there?

Yes. So, I mean things were … and also during that time, I first started when I was teaching at St Mary's, I went up to Lincoln and I started to realise I'd got arthritis in my shoulder. That was, you know, a new … and that, subsequently, was quite interesting because I had Cortisone injections and one of the consultants I saw was Sri Lankan, and that's not irrelevant, and he took it for granted that I was thalidomide. I said, "I'm

sorry, I'm not." He said, "Oh bother, I was going to ask you something." I said, "What?" He said, "Because you are employed and living a full life and living on your own, I'm doing a research project back in Sri Lanka for people with severe disabilities, particularly medical ones, and I was going to ask you if you would mind answering some questions as you are thalidomide." I said, "I'm really sorry, I'm not." And he really pushed me very hard, he said, "Are you absolutely sure you're not? Because if you are, you're missing out." And I said, "No, I'm not." And when he felt my shoulder blades to see where to put the injection in … my joke was, "I'm sorry I came without a map." And he said, "Are you sure about that? Because I think there are some people with a map very similar to yours." And I've never forgotten that. That was when I was about twenty seven.

And did any alarm bells …

No! No!

You were just sure of your …

Yes. I was totally sure. It's interesting though, isn't it?

It's extraordinary that nobody else in your family talked to you behind your mother's back.

I think my aunt was very torn, Diana was, because when she came … she happened to come over to England, she used to come over every year to see my mother and son, the fact that she's a tennis fan and it was the same time as Wimbledon … I'm allowed to say that, she'd say it herself. And because, in that year, in 2009 when she came over, I said to Dave, do you think we should talk to her because my mother was going to go to bed very early so it wasn't unusual that we might have said, "Can we go out?" And I said, "I want to talk to you about something." We spent most of our time talking about mother's care and what was going to happen there because it was all getting a bit fraught by that time. My mother had COPD and she was getting … it was all getting very complicated, she smoked, and it was getting very complicated. She thought it was about her care and I said, "Right, no actually …" and it all came out about how she'd known, how Brian had known and she said, "Now, if there's anything I can do to help" because I told her what I was doing with the Thalidomide Trust and where we were and how far I'd gone. And by then I'd seen Dr Newman and by now it was all about getting the proof and the evidence. Not proof, that's the wrong word, evidence.

So she said to me, "I wanted to tell you." But she said, "How?" I said, "No, no, no, I totally understand." The counsellor was puzzled that I didn't hold it against her. I said, "Oh no," they knew that my mother's relationship with me had to be seen as the most important part and I knew it would have been wrong to have done anything else.

To have taken that decision away from your mother.

Yes. So I could see that. It frustrated Dave I think, my partner, he had quite a few problems about that I think. His own family's so confused.

You're mentioning Dave …

He's not quite in the picture yet, he's almost there. He turns up quite soon.

Well we could either talk about relationships now or we could take a quick break. How do you feel, do you want a quick break?

I certainly need to do one thing that a quick break needs to do. And I also need to be a bit boring with medication as well.

Let's have a quick break and then we're going to go onto …

I know we're short of time, aren't we? I don't want you to starve. Typical me. I'm known for … it's being a member of the WI, I always want to feed people.

I don't look starving, do I?

No. I certainly don't.

[Break in audio].

Okay Liz, it's time to talk about relationships.

Right.

When did you … first of all, have you ever found that your impairments affected your ability to find a partner?

I wouldn't have said so. No. I mean I had a boyfriend when I was at school which, when I look back on it was quite funny because I mention being bullied earlier on and one of the reasons I was bullied was because I had a boyfriend and some of the girls didn't, which is quite funny really. I had a very innocent, hand-holding relationship with a boy two years ahead of me when I was sort of, twelve to fourteen. It was thought to be a bad thing by some of my peers, "Why has she got a boyfriend and we haven't and she's in a wheelchair?" Which is quite funny.

But other than that, when I was going through my Evangelical phase I wasn't really interested and when I was at college I had a relationship in my first year and I then had … I think I was almost too busy but they were not fully … we're not talking here fully physical relationships. I'd had a couple of encounters in my teens, that's how I'd put it, and I discovered that I quite liked, if you like, a cuddle and a kiss. I liked it quite a lot. But other than that I hadn't really sort of gone into … and then, I mentioned early on that I'd been to see

a gynaecologist. Well, my other reason for going was because, at that time, I had started the relationship with a guy who was married, this is where I have to start getting awfully careful here, who was a local man, shall we say, and we were having difficulties actually having sex. It wasn't working and so I wanted to find out if there was any reason why it wasn't working.

Was that your first sexual relationship?

Yes. And I was in my early twenties, it was after I'd come back from college, so I was twenty three. And the reason it hadn't happened before was because I hadn't looked for it. I must have been, yes, twenty two / twenty three. It was quite soon after I came back from college, from uni. And I saw the gynaecologist who said, yes, I could have sex, there was no problem and she gave me some very practical advice on how we might be able to succeed and we did. I discovered that I rather liked … sorry, that's an awful thing to say that it was rather good and I enjoyed it. Well, as I say it was a married man, now this is where it gets a bit murky because he turned out to be the first of a few …

Married men.

I'm afraid so. Not nice.

How did you happen to meet a married man?

Right well he was somebody I got to know … he was local, I got to know him … he was the son in law of people I knew in the village but the marriage was known to be not that good a one. He'd married their daughter because he'd got her pregnant if that makes sense? And that's not a good reason to marry anyone I would argue quite strongly.

A marriage of convenience.

Very much so. He was … he's a very kind man and I thought I was in love with him. Looking back on it now I would now say that I have been in love three times in my life, one of which was the most important. I mean that's me being very candid and I must be very careful when this transcript comes but that's the truth of the matter. And I think it's quite important because I do not know quite … I think I found the physical side of love very exciting and it was something that … I don't know whether I thought I wasn't going to be able to enjoy, I don't know. I do think that was part of it. I was fairly sure I didn't want children from quite a young age and I'm not maternal. I'm extremely fond of other people's children, that makes me sound really odd but I don't mean it like that.

I think a lot of teachers are a little bit like that.

The friend I was close to since I was five, her two daughters, well, when they were growing up, fortunately for me locally and in an accessible place which was lovely, I mean they felt like nieces to me. I love them very much, both of them. And my friend in Hastings, Rosemary, had three. All three very recently have

children of their own and, yes, I love them very much. I was very close to all of them and I think people were quite surprised because I was very good with children and I liked them … I wasn't in the traditional long-term relationship. And I think other people made the decision that because I was disabled that's why I wasn't. But that wasn't what I was looking for. I liked the freedom of having … I mean I didn't see it like this, I liked the freedom of having a life and having physical love, having sex. I mean somebody said to me that I looked at it more from a man's perspective than a woman's and it's possible that there is an element of that, I don't know. I'm not sure.

That first relationship lasted for about a year, I suppose and it ended because it just wasn't going anywhere. And it was right that it did. Then I developed an interest, which sounds as though it's not connected, but actually it is, in going to craft fairs, which was a bit thing in the eighties. And there was a man, a lot older than myself, who did pastel drawings. And it's known to say that he drew me and one thing definitely led to another and that led to an extremely passionate … another married man, passionate on and off affair that lasted for the next couple of years and that was a lot of fun. There was a bit of heartbreak, one thing and another, and I had the ringing me on Christmas day from round the corner when the wife wasn't there and really not … I'm not proud of.

In hindsight maybe.

Yes. But in addition to the physical love … yes, I did love him very much and he also did something which was very useful, I realised that I … it was about four years, that went over a period of time. It was time to leave home. After I'd came back from uni my mother and I talked about it and decided that we would live … I would sort of … it's difficult to explain how we decided. Yes, we would be living under the same roof but we would live separate lives in that I was going to do my own cooking because I was beginning to develop my own interest in that sort of thing and I would have my own social life and we would go in and out and do things separately. So we shared a house rather than I lived at home which might sound a little strange but it worked for us.

It sounds quite nice actually.

It was. But I realised that I needed my own space and although my mother did accept it, when it actually came to it, in 1988, when I found the place in Pevensey Bay and I actually said to her I wanted to move, she couldn't cope. And there was a terrible … that Easter was terrible and I told her … and James was absolutely fantastic on the other end of the line because I don't know how I'd have got through that weekend without him. He was absolutely, you know … because I think he understood, as a parent, to some extent, what she was going through. And he has a lot of respect for her and I think … I will be literally … to my dying day I will be grateful to James, apart from the fun we had, for that weekend because he really did give me the strength to say, "I really am going to move out." Because what I did was to start paying the mortgage and then the bungalow was being adapted over the next year. I didn't move until Easter the following year which was very, very useful. So I actually moved … that was 1987, I moved in 1988, sorry, I jumped a year. It's very difficult to get the years right from that long ago, it's me age, you know.

But it was … that was a momentous decision to make and because of what I said about closing doors, I don't understand children who move out of the building and leave half of their belongings behind, because to me if you've moved out, you've moved out.

Perhaps it means psychologically they haven't really yet.

I think this is true. So the only thing I left behind were a load of vinyl records but everything else went. So then suddenly my poor mother was left rattling in a three-bedroom bungalow with two reception rooms. Not very good. So she subsequently moved the following year, 1989, into a bungalow which is where she lived the last few years round the corner from where she used to live, she still stayed in Westham. And I moved, as I say, to Pevensey Bay.

Now, you not being local would not know that I moved unfortunately into a very damp place, it's low lying, actually it's below sea level, which wasn't the most sensible place for me to move because of joint issues and also because of my sinus problems. So healthwise it wasn't the best. I was blessed with the most wonderful neighbour who I still see, an elderly lady who's an indomitable spirit of the elderly generation, wonderful, and whom I still miss, I'll be quite honest. By a bizarre coincidence her brother still lives in this road, how's that for a strange … isn't that bizarre? It's true, very strange that was.

Now we … James, I think, made the decision once I had moved … he came to see me once in Pevensey Bay and then, not unkindly at all, he gently withdrew from my life and I think he did it on purpose. "She's now established in her life, she doesn't need me anymore." So that's the end, from a relationship point of view, James kind of came to an end there. He reappeared once more, now very bizarrely this was … I didn't hear from him again.

In January 1992 I had a car accident and I broke my leg and I was in a right state at home and he rang me at home. I picked the phone up and he said, "Liz, it's James." And I said, "Hello!" And he said, "I have not been able to stop thinking about you for the last month, what's the matter?" Make of that what you will. So he then rang me a couple of times because he was just concerned, worried, what had I done? Whether I'd … I don't know. Put that as what you like but it's true, it's true.

Now, I had, as I said, a few relationships with married men. I also, at one point, came across, which I will mention for reasons of disability because it's interesting, a man who was in a play at the local theatre and I'd been out for a drink with him and it was quite clear that one thing was going to lead to another. Have you heard of devotees?

Oh, yes.

Right. He was one.

You didn't encounter a devotee?

I did. Fortunately, as things were about to occur, we got as far as the bed, he said something that made me realise things weren't right. So he was duly dispensed.

What did he say? Can you repeat it?

He said something along the lines of, "I've not had a relationship, an encounter was the word he used actually, with someone with your disability before." I thought that was a bizarre thing to say and I said, laughing, "Oh why, do you collect us?" And he said, "Something like that." And I thought this is a bit creepy, "What on earth do you mean?" And, to be fair, he actually explained. So he was duly ejected.

And how did he handle being ejected?

He was completely … he couldn't understand it. Totally stunned. So that was a bit strange. And the interesting thing is he used the word 'thalidomide' and he said … nowadays you'd say get it on but that wasn't the word you used then, with a thalidomide. But he was very disappointed and I remember spitting at him something along the lines of, "I'm not even thalidomide" which is funny when I think about it. But that was very creepy and unpleasant. But most of the time I was having a lot of fun until, you could say, although that's a bit unfair, February 1995 when a teacher arrived at St Mary's School and I'm not going to say any more than that because it's unfair, and I really did fall hook, line and sinker.

And I had three or four months that were just amazing. Yes, he was married. He's … I did actually ring him up to ask him a question last week, he's a very special man, my mother liked him very much. He told me I managed to show him that he should leave his wife and subsequently he married someone else in the school and that's the right relationship. But that's what led to me falling apart totally at the seams. Nothing he did because it's not fair to say that it was his fault, because it wasn't. On the kick back of that, because I just didn't care then, I just didn't care about anything …

Did your mum know that they were married men?

Oh yes, oh yes. She was completely accepting of whatever I did.

Of course she was having a relationship with a married man too.

And I knew that. It makes us sound terribly … but she was only the one as far as I know. Sorry that was a joke. What was interesting was she had a conversation with her brother about me having a sexual relationship with a man who was, at the time, slightly in the public eye. These days, I dare say, it would have been quite fun.

You wouldn't have got away with it.

Oh no. And he said to her, "Do you allow her to do this sort of thing?" And she said, "Who am I to make comments on her physicality, what she's doing, it's up to her." So that was her view. "I'd rather she was doing it here where I can keep an eye on her, where it's safe."

She was quite sort of forward-thinking in lots of ways from what you've said.

She was amazing when it comes to anything like that and I mean her views on young people and that sort of thing … the importance of … she was, oh yes. Unfortunately on the end … I just didn't care. I got involved then with a thug and I nearly married him and I still bear the scars, to this day, on my forehead. There's still marks where he tried to … when I told him he had to leave and he tried to gouge my eyes out

and bash my head in. It can happen … that's why I've always said, "I'm such a strong woman, if I can be taken in, anybody can."

Following that, I decided it was safer over the phone and that's when I met the person in Manchester who turned out to be a wonderfully close friend and somebody who … he should have been my brother, I think, really. And I nearly moved up to Manchester and didn't and thank goodness I didn't. I was actually at my sort of birthday, forward slash, leaving do with the Haven Players and Dave brought me home because I got extremely drunk. This was in 1998 and he sort of never went away. That's how I'd put it.

Dave's the current partner.

And we have been together through thick, thin and sideways and not without some difficulties, ever since. And he wasn't married by the way [laughs].

So about fifteen years almost.

Yes, yes it is.

How long have you been living in this house?

It will be ten years next February so it's nine and a half years.

Okay, so you moved in here together?

Yes. Yes.

So Dave was probably your longest relationship.

Oh, no question. Yes. I mean the reason we came to Polegate was at the time I was working in Polegate … no, I wasn't. Sorry, brain. I was working in Brighton and Polegate was a lot easier to get to Brighton.

And you've never had a relationship with a disabled man.

No, never. I think it's because you could say I've never … I mean I know a few now but I've never … and it's not because I was anti the idea …

You just never were in that circle.

That's what it is. I mean I've had an advance but it's one that I rejected at the time. Sorry, that was very fast forward but that was the best way of doing it.

So now that your thalidomide status is sort of there, do you think you will get more involved with …

I don't know. I talked about it with Annette because she hasn't been for years. I feel now, particularly as I've now got a little bit involved with the health grant. I wasn't able to do as much with Securing Our Futures as much as I wanted to because it all kicked off and coincided with what happened with my mother. She had to go into a home, I had to sell a house in a hurry and then she went back into hospital and she died. Her house sale went through the same time as her …

Hectic.

Yes just a bit and so I wasn't in a place, what with that and then having the counselling. Well, I went to see my MP last week and tried to sort of shake some sense into him … sorry, I shouldn't say it about an MP should I? He's not the most disability aware MP, let's put it that way. I think he's better now.

And so I think … the answer to your question is, "yes, I think I would like to meet a few more … I mean I've had a conversation with Mikey for example and I think it would be good … she's not that far away for goodness sake.

I think you'd get on very well with Mikey.

I was thinking that last weekend because we actually drove through Forest Row because we were on our way to the British Wildlife Centre and I thought, "She's not that far away.

She's great actually. And … there was the big Thalidomide 2012 …

There was. I did think about going up for that but I chickened out.

It was very good.

That's the honest … it was very bizarre because it was over the 25th and 26th; 25th would have been my mother's birthday and it just didn't feel right. That may be a bit silly, I'm not normally that emotional but I couldn't cope. I thought about it.

Well there's a conference next year in March where we will be doing a presentation on the oral history project.

Well that might be more … also it does mean London as well and I don't like London.

It's not London, it's Coventry.

Well Coventry's more straightforward. I know it sounds really strange, I know it's a lot further away but it's actually easier to get to than Central London certainly. We managed Stratford for the Olympics.

Right, what else is needed? She says, nearly strangling herself, which might be … do you know that was more difficult than the other bit.

You did it very concisely.

It sounds as if my feelings were not involved at all but I assure you they were very much. Is there any what? Go on …

Do you continue to have any on-going health problems or do you continue to have any medical interventions?

Okay, right. Let's … now we do need to go back to where things started to kick off and go wrong. I stopped teaching in 1997 but that didn't mean I stopped working full time. I then started, in 1998, when I was better from the transfusion and the insides were under control. I started what I like to think of as my second career which was working as … first of all a training, then an employment officer for people with disabilities. I don't mean at the job centre but initially I was employed by the County Council. I was doing that for five years and I ended up as a Senior Employment Officer and during that time the pain levels in the shoulder, I was having regular cortisol, I now have it under control because I'm taking something I can't pronounce – the non-fish version fairly obviously, massive difference. Brilliant.

I also started … I now can see, I was beginning to get the edges of the fatigue thing although I didn't know it. That job came to an end because it was out-sourced to the RBNI Industries and, for philosophical reasons, I could not go and work for them. So I started to look for other jobs and I got a job as the Disability Support Coordinator at City College in Brighton, which was a great mistake. And Dave was brilliant over that time because that really was a very hard time. And we decided to move and that was really a very … they wanted my expertise but they were doing these adjustments and then turning round and blaming me when it didn't go right and it wasn't nice. And I know I've said it was City College but I know other people who have had other issues, it's not just me.

And when I left there that wasn't … I was very lucky then because then I got a job at another organisation called Workability and I then added another string to my bow because I started working with people with mental health difficulties. Yes, my mother had clinical depression but I hadn't worked … and that was something I really enjoyed and I started working within … I learned a lot, I always said I learned more than I gave in that job. I worked with some great people and I also got a little bit involved with the system of mental health, with Sussex Foundation Partnership Trust although they weren't the Foundation Trust in those days. And I got the Occupational Therapy side and I really … somebody actually said to me, "This is what you should have been doing." And I said, "I've never done this sort of thing before, it's really interesting." And I really enjoyed … and I got quite passionate, and I still am, about community services, particularly for people with low level mental health issues, not just throwing them into the work place without support and the fact that that's a hidden disability and it's not straightforward and I got really interested in that. I pick that up now in what I do now.

And from that, my own health, in 2006 when I was working for them, that's when I discovered the thyroid problem and, again, I praise Dr Baig, the wonderful Dr Baig, again because …

How do you spell Baig?

B-A-I-G, fantastic man, who … it often takes GPs a long time to pick that up and he got it in one. And there was another issue, they were checking some ESR levels because they thought there might be something else, it was a something else that wouldn't have been very nice. And he said … what had actually happened was actually very unusual. I never do things normally, my body never does. And my thyroid had died. He thought that there might be a pituitary tumour, I don't know why he thought that. Something I said made him think that, I've no idea to this day what it was because everyone went a bit mad and ran round in circles for a bit and I wondered what was going on. But it turned out that my thyroid had just stopped working. Now, again, subsequently I have just discovered that this is something else that happens.

That it's thalidomide-related?

There is a link. That's another one.

I do know another thalidomider who has had a lot of problems with her thyroid actually.

It's particularly among women not necessarily in this country. There's been a lot of it in Canada apparently, I've discovered.

This is an Irish woman. She's had on / off surgical interventions.

Well, that was what … they were talking about that for a while, they thought they might have to remove the pituitary gland but anyway they didn't have to. So now it's just a yearly blood test to keep the levels right. My hair was coming out and plugging up the shower thing and things like that. But I just didn't really think about it. You carry on, I know it's a cliché.

Well, the following year, and this is where the thalidomide stuff really starts kicking in although I didn't know it. I started to get horrendous headaches out of nowhere. I have never … I've always been very lucky, pain in my body, constant pain killers all the time. Pain in my head, I was never … stress headache, never. If I had a headache it was a major event, very lucky. I appreciate that. Well, I was having them every day and they were killing me, I really was in a state. I was very lucky or unlucky, depending on how you look at it, we had locally … this is a local issue, we were having issues with neurologists. And neurologists at our local hospital, which is now the Eastbourne District General because that's the main hospital locally. I know an awful lot about the Trust because of the work I do with Link and HealthWatch. Been off sick, come back, was still working privately, not got a very good name, I saw him once and he hummed and haa'ed at me. I'm being very careful not to say his name, I'm very good, I don't want any trouble.

Well done.

Well, I saw somebody who was locuming for him and she said, “You’ve got to have some tests done, this isn’t right, something’s going on. We need an MRI and a CT scan and I want a lumbar puncture.” And I saw then a charming Icelandic doctor whose name was something like Tomsk, I remember because I kept thinking it was like a Womble. I’m sorry I don’t mean to be patronising. You know how sometimes somebody says a name and you just think of something? And he was a bit woolly haired … just my mind, I wasn’t being rude, I really liked the man.

Well, being likened to a Womble isn’t too insulting because Wombles are pretty good.

He was lovely and he actually rang me up with the results when he wasn’t meant to. When the doctor came back he didn’t bother to tell me, he said, “Has no-one told you?” And I said, “No,” and he did what he shouldn’t have done and he was angry because I hadn’t been told. Well I had the MRI and the CT which, from a disability point of view was great fun, they didn’t know what to do! “I can’t do that. My body won’t lie like that.”

Oh, of course. The MRIs are very uncomfortable.

Well this was the problem. And getting onto the beds, it was like some strange game. It wasn’t their fault, it wasn’t the staff’s fault. And, of course, we had the lumbar puncture – oh God. That meant going to Hurstwood Park which is the neurological centre in Hayward’s Heath. So Dave, bless him, took the day off. Neither of us had any idea what was going to happen, no idea. I mean I knew what a lumbar puncture is, I’m not thick.

I’ve heard it’s excruciating though.

Well it is when you’ve got a back like mine. Three doctors, six goes, well it was … I mean it was absolutely horrendous. And there was the most lovely man in the next … it’s really odd at Hurstwood Park because you have day things done to you in wards. So I was in a ward with a long staying stroke patient in the next bed.

And you were actually having the treatment in the ward, not in a separate cubicle?

No, very odd. And he was so nice and he was … and Dave was outside clawing the walls. He said, “I’ve never heard you scream … I’ve never heard …” But this man was so nice and I’ve always wanted to be able to thank him. Eventually a very annoyed anaesthetist … “Oh, why can’t you do this?” Well the answer is because I’ve got, as so often happens with wheelchair users over the years, I’ve got impacted vertebrae. Anyway, eventually they succeeded and I have said I’m never going to have another lumbar puncture except under a general anaesthetic because if that’s the best place to have it and they couldn’t do it …

Well, the upshot of that was there wasn’t anything because they were checking for MS and some other things. So they’d got to check for that. And eventually we drove home, Dave drove home as if he drove on eggshells all the way back from Hayward’s Heath, and of course I recovered.

Well, the CT scan showed some interesting patches in my brain and this is what the doctor rang me up about. He said, “They are consistent with either something you were born with or an old injury – have you ever suffered any head trauma?” I said, “I fell out of a car when I was a child.” He said, “I beg your pardon?” I said, “Well, I did.” And I said, “I’ve been in two car accidents, one was whiplash when I was seventeen and I’ve had … the other one I broke my leg, my foot went through the dashboard, there was no head injury. I’ve not had any head trauma. I’ve also had my head bashed against a basin …” And the poor man took a deep breath and said, “That’s very strange because it looks like either old trauma …” I said, “That’s very strange.” Well, it was settled upon … I saw the neurologist again, he was very cross about the whole thing, it was my fault, I’m not sure what he was cross about but never mind.

It was your fault for being undiagnosable.

And he said, “I think it could be impairment related.” So I said, “Oh well, who knows? I don’t, I haven’t got a clue. I can’t even tell you what I …” And he said, “Well, you’re a thalidomider of course!” So, of course, I blew up at the poor man which is most unfair. Well, of course, lesions in that part of the brain is a thalidomide impairment related thing.

I’ve never heard of that one.

It is, it’s quite a rare one but it is. I saw the … I mean I wasn’t even meant to see the scans but I actually saw them. You can see … I know enough, I’ve seen enough … I’ve worked with brain injury and I’ve seen … so that was interesting. I mean I now take what is actually an epilepsy drug every night to control the headaches during the day.

And does that help?

Yes. And I have what they call daily headache syndrome or something, that’s what the neurologist called it. And they’ve gone down from 50mg to 25. I didn’t realise how much good they were doing until I forgot to take them on holiday. I forgot I hadn’t got them.

So if you stopped taking them …

I’d be laid out again.

It would all start again with a headache every single day.

Yes. And it’s a very debilitating type of headache because it goes round the back of your head and into your eyes. So it was not very good. That was … you can track from there a decline in health quite definitely. I’d subsequently got a … what turned out to be my final employment job, I became a manager at a voluntary organisation, Care for the Carers, and I loved that, I mean it wasn’t without its problems, it was very stressful, voluntary organisation management always is, isn’t it? In January 2009, I felt sick one morning so

I rang up and said, “I can’t go into work.” And I never went into work again. I went on feeling sick and being sick and, well, I mean … I sort of stopped eating.

Actually vomiting?

No, that was what was so strange, it was nausea. And I stopped eating, which might not necessarily have been a bad thing, and that was when, that January … I lay awake thinking, “Something’s going on here. What is going on?” I thought, “Something’s wrong. If I have to stop working …” because I was given two weeks off then another two weeks off and it was halfway through February and I was going to see a gastroenterologist to see what was going on inside. And I started going on the internet, putting my symptoms in, with the internal trouble, with the sickness … and it came back, impairment related … they were questioning that some people with thalidomide, their pyloric stenosis muscle was doing it again and tightening. I though, “How much of a coincidence can this really be?” So I sent off … we come full circle, I actually sent off, not knowing anything about anybody remember, and I sent off an email to the Thalidomide Trust and one to the Thalidomide Society saying, “Look, I know this sounds a bit strange, I’m very ancient but … and I’ve always been told … is there a possibility? This is a rough outline of my disability, what do you think?” I had a lovely email back the following day from the Thalidomide Society.

From Vivien?

Yes, yes. Saying, “We can’t help you, you need to contact the Thalidomide Trust. But from what you’ve said, do it quickly because it sounds as if … good luck.” Lovely, lovely. So I thanked her very much. Two days later I had one back from Martin saying … well, I now know that he knew of my name but I didn’t know that then. “More details please.” That was the start … I know this is this famous thing everybody says at the moment, of the journey which led to the June and my going to meet Dr Newman in the inaccessible place they sent me to … not that … it was funny.

Because he would have been retired by then.

Yes. And I was the missing one that he knew existed on the severe side, the one that his houseman had seen all those years ago.

How fascinating. I’d love to mention to him that I’ve met you if that’s okay?

He might remember. I remember him. I said to him, “I want to know what you’re taking to be this lively at your age. Can we take it?” Which he thought was very funny. He remembered my mother, he remembered her, he actually had met her, fleetingly, but he remembered the name. It’s such an unusual name, Lash, there aren’t many of us about.

It is unusual, yes. Did you ever meet a Dr Fletcher? He was the prosthetic limb …

I would remember, I’m good on names.

Yes, Dr Ian Fletcher. He was the guy who would have fitted children up for prosthetic limbs.

No. Tell you about this for a coincidence … had the phone … December, the doorbell rang and I opened the door and it was a postman standing there and he said, “At long last I’ve got a reason to ring your doorbell, I’ve got a parcel.” He said, “You don’t remember me, do you?” He used to be a limb technician at Roehampton.

So he would have worked with Dr Fletcher.

Probably. Richard. He said, “I’ve been longing to ring your doorbell.” And I said, “You’re not going to believe this one?” It was December before last. Of course he said, “How’s your mother?” And then when I told him I’d just discovered I was thalidomide … “What?” He said he’d always assumed, well, he wouldn’t think any different. So that was a coincidence and a half that he turned up here. I didn’t mind that, I think he thought I might mind but I didn’t. I said to Dave, “You’re not going to believe what happened today.”

Of all places and all jobs.

Exactly. It was like Casablanca, you know.

It’s nearly time to stop, Liz, but can I just ask you one question. I’ve got a couple more questions mostly about the future which we’ll save for the follow up if that’s okay?

Fine, whatever suits you. I don’t want to waste your time.

You’re certainly not wasting my time.

You know what I mean.

But I just wondered … because the main thing in your story is this late discovery that you are affected by thalidomide, did you have an overwhelming feeling when it was finally confirmed … who confirmed it to you? Would it have been Martin?

The final confirmation … well, to me the confirmation was Dr Newman. That’s an interesting one because you got the final confirmation from Dr Newman that, yes, you are thalidomide. And then the acceptance of the confirmation by the Thalidomide Trust and the two things aren’t the same, does that make sense? To me, the confirmation was Dr Newman.

Was your feeling relief? I know it made things difficult with your mum but how did you feel to actually know?

Vindicated that … and a tremendous sense of irritation that it hadn't happened before and, at that time, not being able to understand why my mother hadn't … finding that very difficult. That was 2009 and it was just over a year because it was the August 2010 when she had the stroke. So I only had that year and her health was deteriorating sadly quite rapidly at that time and I knew that it wasn't fair to keep asking what I needed to know. So it was a very sort of mixed … and also I was surprised … we couldn't tell people what was going on. Literally two of my friends I told. And when I told people they were mostly, "Oh, thank goodness for that. We've known for years." That was the … "Always suspected," "We were sure," "Thank goodness, thank goodness." And are you going to get all the back money? Not because I was going to get terribly rich but they thought I should have it which I thought was quite nice. And a tremendous amount of support from friends.

Okay, we're going to stop there for today but we're going to continue next time. What I'll do in the meantime is transcribe this in the meantime and send it to you.

Some poor person, what a job.

And then you can look through it and you might see areas where you think you'd like to say a bit more. I'll certainly see areas where I could have asked you more.

It's quite difficult because I keep thinking, "Did I say …"

The transcript helps that.

It does, yes.

And then we'll bring you up to date with the last questions as well in terms of where you actually are today.

Pardon me, I'm sorry, you didn't really want a burp on your tape.

[Laughs] That's okay.

Well that's changed in the last year or so. So yes. Coming to terms with not working, that's a big one.

Well it sounds like you're quite busy anyway. Thanks ever so much, I've really, really enjoyed hearing your story. It's unique and a little bit crazy.

And I've tried to be honest and not over … not use too many adjectives. Whether or not it's a story that other people want to hear, that's another matter.

Well, we're assuming that people do want to hear these stories. I think interest has been there so far. So I think you can rest assured that the time you first discovered you were thalidomide …

That is what I would like to do, write a book centred around 2009. That's what I've said I want to do because I think that's … I don't want to write an autobiography. So I think that's what I want to do. I did actually keep a journal because I thought it was interesting.

Thank you so much. It was fantastic.

Thank you.

See you next time.

Indeed.

END OF RECORDING