

Thalidomide: Sukeshi Thakkar (2012)

Ruth Blue interviews Sukeshi Thakkar for the *Thalidomide: An Oral History* project.

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So this is Ruth Blue interviewing Sukeshi Thakkar on the 18 September 2012 at her home in Stanmore for Thalidomide: An Oral History project.

Sukeshi, have you seen and signed the copyright and consent form?

Yes, I have. Thank you.

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

Oh dear. Date of birth or date of ... today's date?

Date of birth. Yes.

Okay. My full name is Sukeshi Thakkar. Date of birth is 16th March 1964 and place of birth is Kampala, Uganda, East Africa.

In this first interview I'm mostly going to ask you about your childhood and your birth, your family and school life and any early medical interventions that you had.

Okay.

So first of all could you tell me a little bit about your family background, who your parents were, what kind of work they did, your brothers and sisters.

Right, well, as I told you I was born in Kampala. My father is now a retired GP. He worked in Uganda in a place called Jinja, a small town called Jinja. He graduated in India but married my mother ... my mother was born in Uganda so they went to live in Uganda. Even my mother was born in Uganda so we go right back generations. My grandfather was an industrialist and one of the first sort of settlers in Uganda ... Indian settlers in Uganda and my father's background is ... his father was a journalist in India and wrote for some very famous magazines and newspapers in India. My father graduated from one of the very good teaching hospitals in Mumbai and went to Africa after he married my mother to practice. He had a very good practice, it was very popular in Uganda and because mum's family were all very well known, they all, you know, knew my father very well. He was ... after the ... well, what happened was, sorry, I'm getting confused here. My grandfather came to live with us in Uganda for a little while and my grandfather had a heart condition for which he was taking Thalidomide and when my mother fell pregnant with me she had a couple of episodes where she couldn't sleep and she was agitated and, you know, she was feeling sick. My father had heard about the drug, saying it was a very good drug for sleepless nights and sickness and all that so he gave it to my mother. The medicine that was left over from my grandfather was given to my mother and I think, as far as I remember when they talked to me, she only took two pills.

You sort of naturally moved on to my next question which was talking to you about your parents decision to use the drug Thalidomide. Was it widely prescribed in Uganda at that time, do you know?

No, Uganda was at that time part of the British Empire so it naturally came through after the British Government had approved of it here, the drugs were automatically sent to Uganda if they were, you know, good drugs or whatever. So this was actually for my grandfather, but it didn't say anything ... what damage it could cause for other people. So naturally assuming that it was such a fantastic drug, my father felt that, you know, it would do my mother good, at least give her a few good nights etc. And so he just naturally gave it to her without thinking about anything. And at that time there were no warnings sent out to Africa or no withdrawals or anything like that so ...

Well, why would you not think it was safe?

Precisely, yes.

And was it something your parents were quite open to talk about with you, about their use of Thalidomide or did they find it difficult?

No, they found it very difficult. In fact still find it difficult to the point that I tell them, you know, sometimes I'm very nasty as well, sometimes I tell them it's all your fault, but deep down I know it's not their fault. But it does hurt my dad because he was the one who prescribed it. If it had been prescribed by somebody else, for example a GP or something like that, it wouldn't have been so hard to talk. But because he prescribed it, it is very, very hard even for my mum and him to talk is very hard. And absolutely for me, just impossible because I don't want them to feel guilty. What's happened has happened and through no fault of theirs. So I just don't talk about it with them.

Yes, that does add an extra side to the story that your father prescribed it, that must be quite an unusual scenario I would have thought.

I think there are a couple of Thalidomiders with doctors as fathers who it's happened to as well but you see the pain is even greater because it's your own child and you see the consequences of it every single day of your life and I think the guilt must be eating away.

Did it cause any conflict between your mother and your father?

No. I know lots of families who have had conflicts and have got divorced because of it, but not between my parents because we have a very strong family background as well, you know, family support as well. So no, it didn't cause anything. In fact, you know, I think it got stronger because both felt responsible and both felt that, you know, if they need to take care of me which is the strongest feelings they had, rather than now looking at how they're feeling.

Yes. Moving on to talk about your birth. You were born in Uganda. Were you born in a hospital or...

I was born in my mother's older sister's nursing home. We had a family nursing home, so it was my aunt's nursing home that I was born in.

And do you know how the birth was for your mum? Was it a generally straightforward birth?

I think it was. I'd have to ask my dad actually, I've never asked him but I don't think he was present there. Yes I think it was pretty straightforward, but she didn't get to see me.

So tell me a little bit about that. When your parents were first aware that you'd been born with an impairment, what happened then, have they able to talk to you about that?

Well, I believe – I've gathered stories – I believe that my father wasn't there. He was working in Jinja. Because I was born in a town called Kampala and ... can I shut the door?

Yes of course, yes.

So, I believe that he was called, he was phoned and told that this had happened and to come and see me straight away ... see my mother straight away. I believe she was kept unconscious, she was given sleeping pills to just not wake up. I also believe that I didn't see her for quite a while, about ten days or so and I believe that my father was told, you know, to come down with anaesthetics, you know, we can put her life at an end. Or it was even suggested to go and put me in the jungle where the animals could get to me and just forget about it. But it was a joint decision with my father and my mother not to do any of that and to, you know, keep me and do the best they could with me basically so, you know, families have a lot of input when these kind of things happen. My mother has a large family so there was a lot of input from the families. Although I believe my grandfather just said, "If nobody wants her, I'm going to keep her" so my grandfather was very fond of me. He said, "Nothing's doing, nothing's going to happen to her, I'll take care of her."

Yes yes. It's very harsh some of the things that happened in those days. It would be different now.

That's right yes. There would be a lot of other external support as well, not just family. But at that time, in those circumstances, in that place, everybody was, you know, flabbergasted, nobody had seen anything like this so naturally the first instinct is to ... just how am I going to survive? All sorts of questions go through their minds. What is going to happen to me? Am I going to grow up or am I just going to wither away or whatever. So I guess at that time, although I couldn't understand it when I was younger, at that time those reactions were quite natural and in this day and age those reactions would be totally out of proportion and they would be ...

They would be not acceptable ...

Oh they would be hoo-ha'd all over the world wouldn't they? But the shock of it is the major factor in all of this. Suddenly because you couldn't have a sonography or you couldn't have a look at what the baby was like or anything so I guess when something like me comes out it's quite a shock. It is quite a shock.

I meant ask you as well ... I meant to ask you about your siblings. You said you had a sister. Is she older than you?

Yes, she's six and a half years older than me and she's absolutely normal. Well I don't know if she is normal but [laughs] ... a bit crazy in the mind! But yes, she's married and her husband's actually a cardiologist as well and she's got two sons, one of them is married so she's well settled.

And do you know ... some of these questions are more probably suitable to a western culture's hospital situation, but were your parents offered any kind of follow up care when you were sent home? Did you have any kind of, you know, medical support, or counselling support for your parents?

No, nothing like that. Not in those days or not in somewhere like East Africa, Uganda, no, no. But even when my mother brought me ... I was six months old when I came to this country to be proven that I am Thalidomide, even then she had no support. No medical support, it was more like, well, you know, "She isn't Thalidomide and we don't want to prove it." In fact it was worse she was coming from a completely different culture, a completely different background, a completely different country, it was very hard for her to come and prove that I was Thalidomide, and in fact I think she was the last one, or nearly the last one who did prove that I was Thalidomide.

At what point then did your parents know, or have a suspicion, that your impairment had been caused by Thalidomide?

A very good family friend of ours, a well-known industrialist in Uganda, in a place called Kakira, when he saw me, because he was very good friends with mum he heard what had happened. When he saw me it was very obvious to him because he'd read about it, being a, you know, big industrialist he'd read about it, that this pill caused these kind of reactions. And I think ... I'm not sure, but his son had a similar ... not a disability, but a mental disability that was I think caused partly by Thalidomide as well. So he suggested to my mum, in fact it was his lawyers that wrote over here and suggested that we've got a Thalidomide child here who we'd like to send over and investigate whether she is Thalidomide or not. And on his recommendations my mum came to England for the first time six months after I was born.

And prior to that had you just gone straight home from the nursing home where you'd been born? Had you gone straight back to the family home or were you kept in hospital for any period of time?

Well the nursing home was home anyway because my grandmother's home and auntie's home was attached to the nursing home so part of the building was a nursing home, a seventeen bed nursing home, and then the rest of it was a house. So it was ... but I was taken home where ... we lived in Jinja and the nursing home was in Kampala so I think it was a couple of months before I was taken home.

And did you have to have any kind of medical interventions while you were in hospital, or well, the nursing home before you went back to the family home?

What kind of medical ...?

Did you have any kind of surgery or any medical treatments at all?

No, no. Surgery was suggested when my mother brought me here for the first time to straighten my hands but she'd heard some stories where it didn't work, so she felt it was better for me to adapt the way I was rather than have surgery and then not be able to do anything at all. So she did refuse surgery.

And for the sake of the interview, could you describe your impairment?

I have an upper limb deficiency. Both my upper limbs are short to the point where I can do a few things but I can't do things like undressing and, you know, personal things I cannot do at all because I can't reach places. But I can do driving and cooking and things like that. But the main thing is I wish I couldn't do driving and cooking and could do personal things! [Laughs]. But you never get what you want! If I could have chosen I would have chosen, "Okay, can I do my personal things rather than that." But yes, I've got upper limb deficiency, both my arms are shortened.

And let's go back now to your mum coming to the UK when you are six months old to get you assessed to see if you are eligible for compensation. Obviously you don't remember that, but has your mum described how that process worked, what she had to do, or where she stayed?

We were very short of money in those days because my father was practicing but there were several doctors in the same street as he was, so income wasn't that high. We lived in rented accommodation when we came down here so my parents had to pay for that. The trips were very far apart because they saved and then they sent me, they saved and then they sent me. So trips were quite far apart, we couldn't like, if we were called every week, we wouldn't be able to come. I think my mum came here and stayed a month or so and then would come back because it was very expensive. I mean, you know, hotels and everything ... renting a flat was £12 a week but at that time it might as well have been £200, £300 a week that's how much we felt. Money was hard so it was very difficult for them to keep coming and going but with friends and family, and they borrowed a lot as well, that was how they achieved to get me here.

And how long did that go on for, the coming back and forth?

Up until the compensation ... I think that was about five years, six years that it went on that Mum would come every six months or so.

And so at that moment your main base was still in Uganda?

Yes because my father was earning there so if he had left then we would have had nothing. In fact we were living in my uncle's home as well because we couldn't afford a house, couldn't afford the rent so my uncle gave us his house to live in.

And it was just you and your mum that came to this country?

Yes. The other thing was my father was too proud to accept any money from anybody else, especially my grandfather who had tonnes and tonnes of it, but my father wouldn't accept any of it. So he wanted to do it all himself ... again, maybe it was the guilt factor as well, that, "I've done this and I've got to now put it straight."

So if the assessment and things went on for about six years, do you have any recollection of that? Do you have memories of coming back here for those?

All I remember is coming back here and living in a flat and sometimes us getting lost because we didn't know where the flat was and, you know, I'd tell my mum and she'd be carrying shopping and I'd feel sorry for her, I'd say, "You stand here and I'll go and have a look" and she would say to me, "You're only two or three years old, you can't go off on your own!" You know, those kind of small recollections. Being very cold; not having proper clothes because obviously we come from a very tropical climate and clothes were expensive. Coats etc. were very expensive, so not having the proper attire for that sort of season. My mum struggling very hard and doing the cooking in the flat and all those sorts of little things but not as such going to court.

I remember being prodded and, you know, we used to have to go to these doctors who'd tell us to undress and then they'd take photographs of our hands or limbs or whatever was affected to make sure that we were thalidomide and try and straighten out the arm, or do this or the other with the arm, which was quite painful as well. Those little things I remember, yes, very much so. But at that time my mother was so protective that you feel at least you've got somebody there who's going to be there for you always and so it didn't matter, this will be over in a few minutes, you know? But I remember being left alone in the rooms because mothers were told to go out so they could examine us and that was the worst thing.

Yes that would never happen now.

It wouldn't be happening now, no. They wouldn't leave children with even medical staff nowadays alone.

So that probably must have made quite a strong bond between your mum and you.

It is very strong.

The fact that you've shared all of that together.

Very strong, and like I say, even until the day she had the stroke she was very protective. Anybody says anything to me or does anything to me she'd be there like a cat with her claws out! So sometimes it was too overpowering, but then there was the comfort of my mum being there. And for me, I come from a very, very different society so I didn't leave home at eighteen or I didn't have to go to work at eighteen, you know, they were there to protect me.

Yes and that is different isn't it? Do you know what age you were when you knew that your impairment was caused by Thalidomide or you became aware that you had something different about your body?

In Africa, in Uganda, we were a very close-knit community. Nobody made me feel I was any different, I was included in everything. I would play badminton, I would play... anything that was going: swimming, taking part in everything at school. Egg and spoon races, sack races, everything. I didn't feel any different in Africa but as soon as we left, we left in 1972 to go to India just before you know, the Ugandan incident happened. That's when I started feeling different because I got stared at and I got commented on and I got laughed at. So that's really when I started feeling different and that's when I started asking my mum questions and crying because I'd never come across that. Everywhere I went, everybody knew me in Africa. I had a pet name, they called me "Chinchu" so it was always, "Oh there's Chinchu," you know, nothing like, "Oh there's Thalidomide girl" or anything like that. So I didn't even know about Thalidomide until after I left India and came here.

Right. So you went to India in 1972, that's when you were eight ...

Yes.

And how long would you have stayed ... and you'd had your compensation money through then?

We'd had the promise of compensation money through but it hadn't come through yet. I basically went to India because we had a family home there, my grandmother was there. Not my maternal, but my paternal grandmother was there and we had somewhere to stay because my sister was starting college basically and colleges in Africa weren't that, you know, you only had a couple of choices so we left before this happened and in India I started school because my sister started college. That's where things were getting quite, you know, I found out I'm different from ... I mean I could see it but I didn't think I was any different, you see, I just coped differently that's all. I could see people's hands were longer than mine and, you know, but it didn't sort of strike me that's why I'm different. But going to India and being laughed at and being talked about, and even being, you know ... some people just took the mickey out of me by sort of making actions like me, so that was the worst bit and that's when I used to come to my mum and ask her and cry and say, "Why are they doing this to me? Why am I different?" And then she'd try and explain but it just went over my head until I was about ... we left India to and come and settle down here, after my dad got a job here. Once we were thrown out of Uganda we had no where, no money coming in, nothing, so my dad managed to come to England in 1976, not it was 1974 he came, sorry, and he got a job as a general practitioner here and then he called my mother and myself over, my sister was already here studying and that's when I started school etc. here.

But the trouble was, coming from one background, one country to another country, being mimicked there and all the rest of it, laughed at, and coming here and still getting stared at but no comments made obviously because there weren't that many Thalidomiders around yet, we were still quite young and in our

own little worlds and in our own little niches and schools and not colleges yet. So it was ... I started at a boarding school where I was treated a bit differently as well, over here – not just because of my disability but because of where I came from and my colour.

So you had a lot of different things against you.

Correct.

So you were ten years old and was it the first time you'd been to formal education?

In England, yes.

So ten years old, going to boarding school, in an unfamiliar country, with people staring at you.

Correct, yes. There was only one other Asian girl at the school and she was not a boarder, she was a daygirl so it was very difficult for me. Not only from the students but also from the teachers as well.

Why did your parents decide to send you to a boarding school?

We lived in a village called Edenbridge in Kent and the nearest school was in Limsfield Chart which was about twenty miles away so I couldn't communicate because we only had one car ... I mean I couldn't commute because we only had one car and my dad needed the car for his, you know ... to make visits, go to the surgeries and things like that so it was decided to put me there.

And at this point in time, were you or your parents in contact with ... did you go to any of the events organised by the Thalidomide Society? Did you have contact with other...

Never, no. I didn't want any contact. I didn't want to meet any other Thalidomiders, although my mum always encouraged me, and she did, but I never did. I always refused.

Why was that?

I didn't want to see a reflection of me or I didn't want to know about any other people that were thalidomiders or how they were coping or ... I didn't really care, I just felt sorry for myself!

Yes. You're not the only person who felt like that.

Really?

It's quite interesting ... do you think it's also partly maybe a bit of self-denial that you just don't want to spend time thinking about it too much, you just want to be able to fit in with everybody else?

I don't think that I was at that sort of stage where I felt self-denial. I think I was at a stage where I didn't care about anything else. I was just trying to survive, if you know what I mean? I was just trying to get on with my life and I was just trying to do the best I could and I didn't want to find out from other people how they were doing. It just didn't occur to me, it didn't occur to me.

And so the primary ... the boarding school then when you were ten ...

Sorry can I just stop you? Even the logistics were a bit difficult. If we did have to go and meet other people it would be very difficult because my father's job came first, you know, him putting food on the table came first. And also, I was very into my family if you know what I mean? I was very protected within that environment, I felt safe and I thought if I step out, go and meet other people and things, my world's going to collapse.

Yes. So quite vulnerable?

Yes, very much so, very much so.

But you said your parents did get in touch with other thalidomide children's parents?

Yes they did, finally my mother would attend some of the Trust meetings or something like that that was going on. And she did encourage me a lot but I would just say no ... I was a shy person anyway, I was a shy person, very timid at that time, now I've gone the opposite direction! [Laughs]. But I was ... I was taken from one country to another to another, my education was up the creek because I couldn't settle down in one place. The curriculums were different, the language was different and adjusting to all that, plus having to meet other thalidomiders, plus having to adjust to the weather, the climate, everything was too overwhelming, you know, you have to cut out something in your life and I thought the best thing to cut out was other thalidomiders. It's easier to cut out other thalidomiders.

Yes well you were up against quite a lot in that period of time. What was it like when you left home then and you were actually living in at boarding school, because you were saying that your family network was very supportive ...

I had a carer come with me and she was very familiar to me because she had raised me since I was in India, since I was eight years old, she had raised me. so that helped a lot. But again, because of the circumstances, because I was suddenly taken away from my environment, I felt very vulnerable and I felt ...

I couldn't settle in, I couldn't understand the culture of the English, couldn't understand why I was put there, you know? I felt like my mum was punishing me, in fact. When they realised what I was going through they

decided to take me out of boarding school and consequently we moved away from there and my father went to another place in Kent called Gillingham, Chatham. He got a very good practice there so we moved.

Did you get a chance to make any friends when you were at that first boarding school?

No.

You were quite isolated?

I kept myself isolated because I didn't want anybody asking me questions or, you know... and I had my carer so I had somebody to talk to and somebody to fall back on. But no I kept ... like I wouldn't go to sports or swimming because I had to wear a costume and I didn't want to show my hands so I wouldn't do things like that. So I kept very much to myself.

And you mentioned that you had ... some of the teachers were not terribly kind to you as well at school. Could you say a little bit more about that?

Yes, they didn't ... I suppose they weren't trained to handle a disabled child and I was the only one there. So it was like, you know, one of them, or a couple of students or teachers would say to me, "You know Sukeshi, you're accent's changing and I don't really like it" because I had an Indian accent when I came and obviously when you start going to school with other children, you pick up that accent. Things like that, they were quite snooty and I didn't understand it. The other part of it was, I think I wasn't as grown up as the other girls because I had been so isolated as well so I had a lot to cope with through my life. Not a steady home or a steady schooling, or a steady background or anything. So whereas the other girls had the confidence, I didn't, and that affected me quite a bit, and I think that showed up to the teachers and they took advantage of it.

Did you ... after... first of all, how long were you there at that school?

I was just there a year.

Only one year, yes. And then you moved, so after that you would have been eleven. Did you go on to secondary school?

Yes I did. I went to secondary school but it was a convent.

So it was a church school?

It was run by nuns.

Yes. And what made you parents choose that school?

Because in Uganda as well I went to, not a convent, but an English background sort of school, a kind of a religious school and they felt that I'd tried the public school and it hadn't worked so go back to, you know ... and they wanted to send me to a girl's school so I wouldn't be teased by boys as well, so that was the only school that we had in that area and it was convent and religion didn't really matter to my parents.

Did they have any religion themselves?

We're Hindus, yes, but they're not overly religious in the sense that we do believe in our religion but then we respect other religions as well. And whether you go to a convent school or Muslim school, or anything, you're going there for your education, you're not going there for your religion. So they were very open about it and very, like what can I say? Modern about it.

Was this a day school, this secondary school?

Yes, it was, yes.

And it wasn't a special school in any way?

No.

And how did you fit in there? Was that a happier experience?

No. The girls were pretty nasty! Again, I was disabled, I was an Asian girl, I was from India, I didn't dress in short mini skirts and things and, you know, I was quite ... not their type of person if you like. A couple of the girls were nice to me. And the other thing that I had was I couldn't mix with the girls because I had my own problems in the sense that at lunchtime I couldn't sit with them and eat because I had to go home to use the toilet. So I would be waiting for my dad to come and pick me up to take me home to get me lunch and to meet my toilet needs. So I couldn't mix with them at lunchtime or break time or anything. Sometimes I'd be waiting for my dad and if he had too many calls, because we only still had one car, he wouldn't be able to pick me up so I'd be waiting there until the end of lunch and then I wouldn't go to the toilet or anything and so you feel uncomfortable, so you don't want to talk anybody, you know? So it's embarrassing to go and tell, at that age, to other girls, what's going on with you. So you get isolated, so it's, "Oh, Sukeshi doesn't want to mix in" but that wasn't the case, it was because I had so many problems.

Yes and when you are younger like that, it's very difficult to...

It's embarrassing.

You look back as an adult and you think, "Why didn't I just say something?"

Absolutely, yes.

But you can't at the time can you?

No, you can't, you can't. I still find it difficult, but if I'm desperate, I'm desperate, you know? But I still find it difficult. If my carer's not there and I've gone somewhere, then it will be eight / ten hours before I can go to the loo. So it's still very difficult. You don't want to be asking everybody, "Can you pull my pants down please? I need to go to the loo," you know? But if you have to sometimes, you have to. And some people who ... like my sister for example, she'll say to me, "Why are you worried? You ask anybody" and I say "No I can't. It's easy for you to say because you can do it yourself." She says, "I wouldn't be embarrassed." So I say "Yes, well, let's try it for a day".

I bet you she would.

Yes, she would. If I tied her hands behind her back and said, "Okay, you've got the whole day to go and do what you normally do, let's see how you cope," you know? So it's easy to say, but when you're in that situation it's very difficult.

Absolutely. And especially when you want to be independent and you want to be doing things yourself, you don't want to be having to ask for help all the time do you?

No. Especially when, you know, it's a very private thing. If I want somebody to pull my zip up, that's a different thing. "Can you just pull my zip up?" But telling them to take me to the loo is very, very personal.

Absolutely, no I totally agree with you. And there was nothing at the school ... the school didn't try to adapt in any way to accommodate any special needs you might have had?

No, no. Not at that time. I don't think they knew that much.

And do you know... when you were at school ... so you must have made maybe a couple of friends?

Yes actually I did, I did. Two girls who were actually very nice to me but still I couldn't tell them about my problems ... not that close that I could tell them about my problems. But it's really weird because they've done a reunion of the convent and through Facebook they contacted me and I got a phone call from one of them the other day and she said, "We always liked you," and I thought, "No you didn't! [Laughs] You were all nasty to me!" "No, no, we always liked you. We always talk about Sukeshi and where she is and what she's doing," and, "Well why weren't you nice then, you know? Why are you suddenly nice now?" I've had a lot of publicity now, you see, and they all want to say, "Oh she was at school with me, she was at school."

I understand that, I understand, you know? But it was that time that I needed the support and everything and I've fought my way up now and I don't need people like that, negative people like that around me. But it's nice of them, they invited me to their reunion and everything, and "We must meet up" and all that sort of stuff. And I thought yes I'd really like to meet them, I'd really like to drive my car up there and show them you know! [Laughs].

But I'm not that sort of nasty, I don't have a nasty streak you know. But it would be nice to just go and see them and say hello to them and show them what I've achieved.

And in terms of things like achievements, how did you get on at school with education? Did you have any subjects you were particularly good at?

Yes, I was. It's really weird because once being told they don't like my accent, I was very good at English Literature and Language and I was very good at art.

The two best subjects.

Yes [laughs]. And I always had a flair for designing so ...

And at that time did you have an idea of what you might want to do when you were older? Were you sort of chewing over some jobs?

First of all I wanted to be a marine biologist [laughs].

That's a bit different!

Then I wanted to be an English Literature teacher. And then I decided ... what else did I want to be? I wanted to be lots of things, you know, lots of exciting things that I knew I couldn't achieve, but I could dream of. Education wise, I so much wanted to go to university but I couldn't. I couldn't because a) my parents didn't have that kind of facility to send me to university, b) because my mother didn't want to let go. She didn't want me to go off far away without her. And also I think I struggled with my education because of all the different places I'd grown up in and had to study in. So I really struggled, although I managed to get my ... I think it was eleven O-levels then and I got three A-levels, and I started a course in English Literature. I left ... I had to leave it half way because of the problems I was having living there – my carers kept changing so it was very difficult for me.

Eleven O-levels and three A-levels doesn't sound like you were struggling.

Well I was struggling in the sense that ... logistic wise I was struggling, not education wise but logistic wise. And then if you're not settled when you're studying it's very upsetting.

You can't concentrate.

No you can't concentrate. And they were more concerned with my sister getting a better education because she needed to get married. So it was more concentrating on her. And, of course, they can't give me one hundred per cent concentration because she needed their attention as well. So it was difficult for me that way.

But I managed to do a lot of things. I did my fashion designing course which I did. Simultaneously my sister was at college so my father had got her a flat at Baker Street to go to Chelsea College, and there's a fashion school there called the American School of Design, so we both could live together. I had my mum there as well because it wasn't that far away and then I could go off to college ... just walk down the street and then I was at college.

How old would you have been then?

I was twenty-two when I went to college.

That sounds like quite a nice time. Living with your sister and...

Yes, it was a good time, yes, yes.

And what were people's attitudes to you then? As you got older... so at college did you have ... you didn't encounter any of those same sort of prejudices or people being difficult around you like you did at school?

No because then by that time we were in the late eighties, nineties so no I didn't. I was well accepted. I had problems with sewing a little bit so I was helped there, lots of help. The teachers were excellent, they were very sympathetic and very helpful as well. It was like ... it's a big college so you're in your section, so my group I was quite comfortable with my partner ... you work in teams ... so with my partner I was very ... she was very helpful, very helpful indeed, you know? So it made me feel good as well. And I think living in the big city as well helped. Having my sister there, going out with her in the evenings, you know, generally enjoying ourselves was very nice. It was a very good experience, at last! [Laughs].

And was your sister generally supportive of you as well?

Absolutely. Very protective. Yes, she was like a second mum and she was that much older than me as well so she felt she needed to take care of me, and absolutely she took my mum's place when my mum wasn't around. Very protective, looked after me. I mean we'd have our sibling rivalry, we'd have our fights and stuff, but that made me feel really good, because she was treating me just like she would any other brother or sister.

Yes. And so did people ask you ... when you were a student, did you make friends then, when you were on the fashion course?

I was ... making friends was very easy for me, but I was very much wrapped up in what I was doing because I was loving it so I was concentrating more on that... designing for my friends, not in college, but out of college as well. We have a large Asian community here, most of them from East Africa, most of them from my town. Ninety per cent of them knowing our families, ninety per cent of them having been my father's patients so that was a very nice thing although I wasn't designing for money at that time, I was designing more because I really enjoyed it and wanted the experience. So I'd just design little things for my friends, and that kept me busy and that kept me fulfilled as well. So it was exciting, you know, all of a sudden there was this whole wide world and I was part of it.

Yes yes. And your relationship with your sister ... you mentioned something a moment ago, you said it was important for your sister to get an education because she was going to get married. Were you treated differently to you sister by your parents in that respect?

Not differently, but I think deep down they knew that it would be very difficult in my community and they were very concerned because they didn't want anybody coming along and marrying me for my money. That was their main concern because they'd heard stories as well that the money disappears and then the husband disappears, and that was their main concern that a gold digger, you know, or whatever you like to call it. So they felt that I would be better off ... they would be better off letting me stand on my own two feet, getting me strong rather than getting me married and then collapsing that way. So I think their priority was to get my sister married first and then to see what comes along with me. And I totally believed in that. I still do, I still do. I still feel like they were absolutely right because it does happen, you hear stories, not just with disabled people, but with normal people as well.

Yes absolutely. It sounds like they were ... in their minds they'd really thought through what was going to be best for you all the way down the line from what you've said so far.

Yes that's right, yes, although people think that they hadn't, that they should have let me go and find my own way etc. But they were doing what parents do, protecting me. And maybe over-protecting me a little bit because of my disability, but they ... I look back at it and I think absolutely, if I had a disabled child, maybe I'd do the same thing as well. Especially in my community and with the publicity we get and everybody knows we get money so I think I would have done that.

Yes. And on-going health problems. Was anything going on at all where you had to have any regular medical check ups or...

When I was twenty six I turned diabetic, I got diabetes.

Was that Thalidomide related?

I don't know. I don't think so. But both my parents are diabetic so it's perhaps hereditary. So for that reason yes, I would have to have check ups and I would have to go for blood tests and this is when I discovered that blood tests were very, very...

I've heard this from a lot of people – very difficult.

Oh, next to impossible, next to impossible. Luckily we had a very good phlebotomist where we were in Kent. And plus my father being in the business, as you call it, he used to take my blood before. And then the phlebotomist found a way to take my blood so it was easier. But then when he left, it became more difficult and more difficult and more painful, so I wouldn't go at all. Even testing my blood sugar was a bit too much. Otherwise, healthwise, it's the way we've used our bodies over the years. Yes, the back and the shoulders and the neck.

You were never offered prosthetic limbs?

I was. I was.

Did you ever try those?

I did, but they didn't work. I was sent to Roehampton Hospital for a week's training with prostheses, but I wasn't comfortable. In fact, it was very, very painful. I was offered the operation, I was offered prostheses, but the way they were made, it just ached. You wear it for an hour and you've had it.

They were very heavy as well weren't they?

Heavy and cumbersome and also painful. Really painful – they dug into you. If you moved your arm it dug into you, so you'd sort of flinch, not wanting to do anything, so you'd just sit there ... what's the point of just sitting there? So I used to cry every time they put them on so my mother decided I was better off without them. But yes, we were offered all that, but to no use.

And any other gadgets that were useful like um...did you get an adapted car or...

Yes. There are often little silly things like a zip puller, and a button hole thing. We were taught how to get on the bed and pull our trousers on. Yes but, sorry to say, but when you're made up, your make up and your hair's all nice, you don't want to sleep on the bed or get your trousers on, you know, or pull a t-shirt down and ruin everything, but that's the way it was at that time, you were taught things like that.

The adapted car came when I was sixteen and I think that was my, up till now, greatest achievement. I love it. I love driving, I love being independent. It gave me such a sense of power and although in the beginning it was very difficult, because we didn't have the power steering and the comfortable cars that we have now, I had a little Mini Clubman Estate and it was so hard to park, so hard to drive, but I was determined. I was determined and my father didn't want it because he didn't want me ... he thought that I'd be having accidents all over the place and hurting myself even more. My mum was very encouraging, in fact she actually had arguments with my father about my driving. I passed my test at seventeen, the first time around, and I've been a driver ever since in the house. It's more appreciated now because my father can't

drive, he's lost his sight, and my mother is bed bound. So, you know, if I wasn't driving, I don't know what I'd do.

Yes, thank goodness you went ahead with it.

Yes, that's right. Yes, yes.

So, career. So you did your fashion course.

Yes. I spent a year in India. A year out in India doing my fashion as well so, looking back on it, it was so different from the school I had been to in India. At this stage I was in my twenties. I'm not boasting, but I had a talent and the college I went to recognised the talent and the students recognised the talent and I was treated very differently this time. So I wasn't looked at from a view that, "Oh she's disabled, she can't do anything," because I'd proven my talent, it was like, "She's somebody to compete with."

Yes and they're looking at you for what you do which is very important in life isn't it?

Yes, which is what you should do, rather looking at what limbs are missing or what's missing. It's what you can achieve from even those missing limbs. I got a part-time job with Zandra Rhodes when I came back.

Wow!

Yes, I loved it!

Amazing!

But she stole all of my designs so I gave that up [laughs].

I imagine she was rather a feisty character to be around as well.

Yes she was. And because I came with the Indian sort of look. Indian outlook of colours and designs and patterns and all sorts of different things, she was very pleased to have me there. But she paid very little and she steals designs I'm sorry to say.

Probably I would think that a lot of people who have been designing for a long time and get bright young stars coming along, it would be very hard for them not to just lift a few ideas.

Yes, yes absolutely, because you want to maintain your name, you know? You want it right at the top and you don't want other to come and take your space! And then if you're employing them, naturally they're your designs if you're employing them.

Yes. Would that have been your first job, then, when you were her assistant?

Yes, that was my first job.

How long did you do that for?

I did that for about six months because I was unhappy with the work situation, I was unhappy. The fashion world is a very weird thing and I was unhappy with the atmosphere, my colleagues, everybody's grab, grab, grab there and I had never been in that sort of environment where we were competing with each other continuously and so it was a bit overwhelming for me and it wasn't my scene at all.

I was involved in the art world for a long time and it was exactly the same.

Yes, I'm sure.

Just massive egos. And in the end you think ...

"I can't handle this."

So yes, I know what you mean. At any point when you were seeking career opportunities, did you encounter disability prejudice, or did your impairments get in the way of you getting anywhere in your career that you wanted to be?

Absolutely, all the time, every step of the way, every step of the way. When I didn't have a job I remember ... when I was at school in Kent and you know how kids like to do summer jobs, something like that, to get the experience. I went to the Job Centre and the lady at the desk told me, "Well we can't put you in front of a desk because you just wouldn't look right" and it made me really, really ... it really hurt me.

I'm not surprised.

Well saying that to somebody, that, "I can't put you as a receptionist or something because you won't look right because of your arms," you know? It's very degrading and very insulting. You know, I've got a brain and I am using my brain even though I can't use my limbs but I can do the job as well as anybody else.

And wouldn't intelligence and politeness matter as much as having the right shaped arms?

Exactly! Exactly. And picking up the phone, and answering the phone is not a scientific job, or rocket science or anything like that, anybody can do it, anybody intelligent can do it. And I do it at home, I used to take my father's calls, so I was pretty good on the telephone and I thought that would suit me. That got me really down so I started doing courses, you know, little courses, mini courses to help me. I did Travel and Tourism, I did lots of other mini courses that I thought, "You know, okay, if I've got them all behind me" ... then what happened was, I became quite competitive because doing these courses I wanted to achieve the highest standard so the competitiveness started showing in my fashion designing as well. I wanted to prove ... it's all about, with Thalidomiders I think, it's all about having to prove rather than, you know, because of the attitude of people ... to having to prove, "I'll show them, I'll show them," you know? And I think it still happens with me.

And do you think that's different to other disability groups. Do you think there's something different about Thalidomiders' need to prove themselves, in your words, than other disability groups, or would you say that runs across the board with any disabled person?

Partly it runs across the board, but partly I think it is very much to do with Thalidomide. As you say, disability groups are wider, if you see what I mean? Thalidomiders, we're only so many people in the world, and hopefully not likely to have another generation coming. Whereas people with Multiple Sclerosis, that's going to go on until research has been done and Motor Neurone and things like that, it's going to go on until research is done and we can totally stop it. But Thalidomide was man made anyway, so hopefully that will be the end of it once we're gone. And so I think it's more important for us to prove that as a Thalidomide community, as a Thalidomide disability group, we achieved a lot.

Yes, interesting. And I know you said when you were younger you didn't want contact with other Thalidomiders, you needed to just sort of knuckle down and just cope with all the things you had going on ...

Correct.

... did you have a period of time where you changed your mind about that?

Yes, yes. This must have been about ten / twelve years ago. I attended the first Thalidomide NAC ... do you know what NAC is?

Yes, yes.

NAC meeting in London. The very first one.

What changed in your mind then to make you think, "Actually I will now get to know other Thalidomiders?"

I think a little bit my mother. She wanted to meet other thalidomiders and she said, "You know I'd really like to meet them." I think another factor was I met Geoff ... do you know Geoff Adams-Spink?

Yes, I interviewed him.

Oh right okay. So I met Geoff and Geoff was very friendly, very forthcoming, very protective actually and easy to talk to. And I felt, "Oh okay, if all thalidomiders are going to be like this, I'd love to meet them". And he said to me, "Just come to one of the NAC meetings, just come and see, and bring your mum." So that made me feel good, that I'm not going on my own, you know, I'm taking my mum with me. And I went there and everybody was so friendly and there was so much going on that I didn't know about in the sense that there was campaigning going on, people were involved in all sorts of things. I had the confidence, like I say, because of what ... I'd started my business etc. so I had the confidence there as well. And I thought, "Oh this is great! It's like a small little world, a different small little world. And I belong to this world, I'm going to be accepted in this world, I don't have to prove myself here, I don't have to fight here. I'm just there, you know? So it made me ...

Yes, you can ask for a straw with your drink without anybody staring at you.

Absolutely. I can ask, "Can you lift the glass? Can I have a different glass because this one's too thick and I can't handle it? Can you bring my plate to the table?" There were all sorts of things I could do without even looking around and seeing if anyone is listening you know? I felt free, if you like. And so, with Geoff there, and with other people I met there, I felt I wanted to contribute as well, so I got involved in ... so much so that I got elected onto the NAC as well. I did two years with the NAC.

Now my subject after that became psychological issues. I went through a bad period where I met somebody and they really took advantage of me and it affected me psychologically.

Is this a relationship with a partner, or a friend?

Not a relationship but a friend who took advantage of me.

How did you meet them?

Through another friend, through another friend. And I've always been shy of men, very shy, because I don't know what their reactions will be to me. I always felt that people were laughing behind my back anyway, that was always the feeling there. Sometimes I wouldn't care but then sometimes if I liked that person very much, it would hurt. So when this person took advantage of me I just broke down, and I needed psychological help. It took me over a year to get that help.

Can you say a little bit more about it, if it's not too painful, about how the person took advantage of you?

Well, pretended to be a friend, pretended to be a friend, pretended to like me. Pretended that they wanted to be a business partner, took advantage money wise as well – I was foolish. So that sort of advantage. I found out things about them that they just ... the good thing that I found out was it wasn't just me they were taking advantage of, there were other people that he'd done that to. And I'm still friends with him, but I keep away. But he tried to make me believe that I was mentally unstable and I started to believe that.

Oh that's very dangerous.

I started believing it. And I would hide it from my parents because I didn't want them finding out. Because they didn't like that person and I didn't want to get away from that person, do you see? Because they had a hold on me. And so I got to a stage where I asked for ... he would tell me if I don't get that psychological help, he was going to walk away and that was my worst nightmare. Deep down I knew I didn't need it, but I just wasn't strong enough to do that, so I went to my doctor and told him that this was what was happening. Didn't tell him the truth of course, that I needed help, was getting depressed etc, and finally a year later, they got me that help. By that time I'd deteriorated a lot because bombardment from this person day in, day out, "Oh no you're doing this, you're a liar, you need help" and in the mean time he'd ask me for money so it got to a stage where I was just literally just thinking of committing suicide. It got to that stage. And hiding it from my parents was the hardest thing, because they'd know there was something fishy going on.

How long did it go on for, that sort of cycle with that person?

Two years.

Right, that's a long time.

Yes it is.

And how did you break it? How did you stop?

I went to the psychologist at the local hospital, I was finally referred to the psychologist. I went on anti-depressants and I'm still on anti-depressants because coming off it is not very easy and the psychologist ... I started talking about everything from ... it started with him wanting to come to the psychologist so I got to the psychologist and I would talk about how horrible I am, what a liar I am, and I wanted to get out of that cycle. Then slowly the psychologist, I think it must have struck her that this man was manipulating, so she said, "Do you mind if you come alone?" And I thought, "Thank God she's said it and not me" you know? So I went alone and she brought me out of it, slowly saying what's happening and I told her, "I'm not going mad and I'm not a liar and I'm not a cheat, but I think I'm being manipulated. I think," I said. And she said, "You are, because you're quite a strong character otherwise and you've got to get out of this, and I don't want you to bring him here anymore. And I want to talk to you."

It sounds like he was really trying to control you. I mean, to go to a meeting with a counsellor or a psychologist with you, I mean how can you possibly speak freely when ...

Because he wanted to know what I was saying. And to him, the truth was that I was a manipulative liar, that's what he wanted to prove to the psychologist, that that's what I am. And once I started visiting her on my own I got the confidence back and I just said "Enough is enough." And I said to him "Look, I can't do any more money. If you want to be my friend, be my friend, if not just walk away." And I got the strength to do that. But no, he still tries, he still tries.

Even now?

Oh yes, up to this day. But he knows now I'm very strong so he's changed his tactics, so he wants to be very nice to me etc. and not bring these subjects up. But I am very strong now. I've become even stronger because I'm looking after my mum and I need to be there for her. She's my priority now so...

Yes and this guy though, was it ever on his part, do you think, on his part, a romantic attachment to you?

He wanted me to believe that so that the string wouldn't ... the rope wouldn't go, so he wanted me to believe that. And because he wanted me to believe that, and because I was really low, I did believe it, and the thought of him leaving me was like, "That's it, life's finished."

Yes, yes. And would that, in a way, would that have been your first serious relationship with a man or did you...

No, I had a couple before. They were serious but it didn't affect me as much as this had because I was thinking I have a very good friend, he'd take me to the theatre and he got me involved with the theatre and music and this and that and I was having a good time and I thought, "Oh good, I've found a great friend here" but then I was paying for that friend in a way wasn't I? It wasn't just £10 here and £10 there, it was thousands and thousands.

It sounds absolutely awful. Thank goodness you got away from it.

Oh he still tries. He still tries to manipulate me, but now he knows that I've got that ...

Yes, it sounds like he doesn't have that hand of control over you any more.

No, and I'm not, "Yes sir, no sir, three bags..." He would say to me, "I'm your boss. If we go into business together, I'll be the boss, but you put up the money." And thinking about it, I thought and thought and thought and when I became stronger I thought, "No way, if I'm putting up the money, you're working for me." You know? How can I be so foolish to let a man take over my life like that?

You wouldn't be the first person in the world.

I know, I know. So that was actually quite comforting that it wasn't because of my disability because I always thought it was because of my disability, but that's comforting that you hear stories about this ...

Oh many stories. In both directions don't you? Sometimes it's women who manipulate men and you know...

Oh, absolutely yes. We've had that in the thalidomide community as well.

Yes absolutely. So obviously you haven't had children.

No.

Would you have liked to have had children? Do you think you would have seen yourself as someone who'd got married and had children if you'd had a different life all over again?

I do wonder. I don't see myself, but I do wonder. Especially when I was bringing up one of my sister's sons. She has two sons. And he was at boarding school here in Epsom, so I was sort of mum to him because he came at thirteen and I would go and pick him up every week and bring him home, take him shopping, feed him, buy his clothes you know? And then go and drop him off and he'd ring me if he had a problem or anything like that. But he was thirteen then and that was okay, I wasn't changing nappies or anything like that! [Laughs]. I sometimes do wonder if I had had children how I would have brought them up, if I had a husband, what kind of a husband, what kind of a life I would have had. Yes, sometimes I wonder. Then I think, "Oh I'm so glad I didn't have to make those school runs and get up early in the morning"... not have a husband who I have to ask things. You know? If I want to spend something I don't have to ask anybody. I can go and do it myself, spend ... how I want my house is up to me. What I eat is up to me, you know?

Yes, you get quite a lot of freedom in the way you choose to live.

I think once you get past that age of where you do want to get married, say in late thirties or early forties, you've passed that age where you think, "I'd love to get married and settle down and have children," then you become selfish. Then you say, "No, I'm really enjoying my life. I don't have to get up early in the morning. Don't have to cook if I don't want to. I can watch whatever channel I like [laughs]. I can be at home or go out and stay out all night if I like," you know? So I then think that after a certain age you change your ideas and you think, "No, it's a good thing that..."

Yes, to have some complete independence.

And then the heartache of it. The children, the education, the marrying them off, the grandchildren, all the rest of it. It has its advantages and disadvantages but if you find a good person then it's a different thing. But if you're unlucky, and I always had a fear of somebody marrying me for the money and not myself.

Yes, I can imagine that, yes.

I think my parents always ... my mother especially always had that fear. I mean, you don't have to get married and have a husband to have a good time anyway.

Exactly, there's plenty of things you can do in life. And so, for the sake of the interview, because I think we talked about this off ... before we started recording you. You live here at the moment with both your parents.

They both live with me, yes.

And you were telling me about your mum's stroke that she had recently. Could you tell me that again for the interview? So your mum was your main carer you were saying.

Yes she was, although I do have a carer, but my mum was there all the time for me. In fact, we were more than a mother / daughter relationship, it was more like now we were friends getting to this stage. We did everything together, like if she went to India, in a few weeks time I'd follow and we'd have a good time there. We had a pact that if she's in India, she took care of me there, if we were here, I'd take care of her here, in the sense that I'd do all the bill paying and looking after and grocery shopping and all that in this house, and she'd do that in India. So it was a holiday for her here, and a holiday for me there. And we were in business together as well so she would handle my ... the embroidery and the buying of the material and everything over there and I'd send her designs and she'd have them made for my clients, so we were in partnership in that way as well. We became really good friends, really good friends.

Absolutely, it sounds amazing.

Unfortunately, I had a fashion show ... well, in November one of my very large fashion shows with two hundred / three hundred people attending and, for the very first time, my nephew was modelling, my sister's older son was modelling. I think she got a bit over-excited and after the fashion show she was just sitting in the chair and next thing she was on the floor. She was taken to hospital and they said she'd had a massive stroke. Three quarters of the left side of her brain was brain dead. In the hospital, the consultants told me that there was no chance of recovery. Even if she did, she would be like a vegetable and the best thing for me was to let her go. I couldn't believe it when they said that, I really couldn't believe it, and I totally refused. I said, "Whatever it takes, you have to keep her going. I'm not going to sign no resuscitation order. Plus knowing a little bit about the medical background, having my father to support me, and my brother-in-law who is a doctor, my sister's a microbiologist so we have a lot of medical background and my brother-in-law was communicating with me every day, four or five times a day about my mum and he said, "No way, don't let them do that. Don't you sign any papers or anything." And I said to the doctors, "No I want to keep her going."

Two months down the line, they hadn't got her sugars under control, they hadn't got her physiotherapy, they hadn't got her anything at all. She was just lying there in bed, not able to do anything. The consultant called me and said he wasn't able to do anything for my mother anymore and that either she should go into a nursing home or I could take her home, but that they couldn't keep her anymore because there was nothing

they could do, they'd done their best. The consultant ... when she was about to be discharged, she got a high temperature and she had diarrhoea and she was on antibiotics and the consultant wanted me to take her home in that state. And I told him, "Look, people come into hospital in that state, they don't go home in this state. No way am I taking her home. You first fix her. You first get her diarrhoea under control, her temperature under control and then I'll take her home." Her insulin and her diabetes under control because she was staying very high. This was ... they were going to send her home on the Monday, and they finally ... when I refused, they got it under control on the Thursday and they said she's ready to go home on the following Monday. And I said, "Yes, if she's ready, I'm ready." The consultant said to my sister, "I think your sister's panicking now that she has to take her home" and I told the consultant, "I've never panicked in my life. I've had so much more to put up with than having my mum home in this state. I've had a lot more going on in my life that I could have panicked at, which I haven't done. This is nothing. I will take my mum home, and I'll show you. And I bought her home ten weeks after she'd been diagnosed and had her treatment. And she came home with a PEG feed ... you know what a PEG feed is?"

Yes, yes.

With her diabetes way out of control. With her not able to turn in bed or anything. With her not able to eat, drink, not even drink. And not even able to talk, say anything at all and drowsy all the time. In the eight months she's been home, she now can turn over in bed. She's off the PEG feed, she's eating by mouth, she's drinking with a cup. She's sitting up in bed for half an hour / an hour. We're standing her up for five minutes and she's not talking but she can make us understand what she's saying.

She's brighter yes.

And I took her to the hospital for an x-ray, three / four weeks back and we took her to the consultant and I said, "Mr Cohen, this is my mother. Look what you said and look where she is right now." And my mother was thirsty so she asked me for a drink and I gave her the drink and she drank. Because he said to me, "She'll never be able to drink out of a cup" and she drank and he said, "Wow, that's amazing." And he said, "That's family dedication" and I said, "Well you were saying that I wouldn't be able to cope. I've done much better than your hundreds of staff here would ever have done."

Yes. And isn't it interesting from your story, there's a whole circle where a lot of the medical profession said to you, don't bother, just leave her and your family didn't give up on you.

Yes exactly and the other way as well where she had to take care of me when I was born and now it's come full round now, and as she's getting older I'm taking care of her. And in such a manner that she really is like a small baby now.

How aware do you think she is of what's happened to her? Do you think she's all there in her mind but she can't communicate?

Yes she's aware. Not all there, she does forget. But she's aware of what's happened to her because she cries, especially when I'm looking after her, feeding her or giving her cuddles or anything, she really cries.

Because she feels that she's meant to be taking care of me and it's the other way round now. And I say to her often, I speak to her. I say, "Mum look, don't worry, you took care of me when I was little, it's my turn now. I have to give back something." And she cries and she laughs and she gives me a hug. So she is aware, she is aware. And she doesn't want anybody else but me. If I go out, she won't eat. If I'm even in another room she'll cry so that I'll go running to her. So she knows that this is my be all and end all of everything. And the roles have really changed, really reversed, even with my dad. He's eighty-seven, he relies heavily on me now. He can't drive so I have to take him to all his appointments. I have to drop him off at hospital, tell him to wait there, go and park the car, come back, get a wheelchair, put him in the wheelchair and then take him to his appointment.

And how has he reacted to your mum's stroke?

He hasn't taken it very well. But he knows that if he breaks down, then it's going to be very hard for me.

So it's been a really hard year for you.

Oh, yes, a terrible year. A terrible year. In the hospital where mum was, I stayed there continuously at night, so again because I can't go to the bathroom, the last thing my carer would do, at ten o'clock, she'd leave me and come here to look after my dad. So she'd take me to the loo at ten o'clock and then I'd drive home at eight or nine o'clock in the morning, until then I can't go to the loo. If I can't go to the loo, I can't drink. I mustn't drink, because then I'll want to go to the loo, so a lot of dehydration was taking place as well and I'm diabetic as well, so it's been ... like you say it's been a really tough ten months. But I'm not looking at those months that I went through, I'm looking at what I've achieved.

Absolutely, and what there is still to achieve as well.

Absolutely. I know I can never get my mum back, fully get my mum back, but whatever quality of life I can give her is, you know, it would be amazing. And that's why I'm building the room and everything for her as well.

Ah, I was going to ask you what that building work going on outside was.

They're building a room and a bathroom. Excuse me, she's crying [interruption in recording]

So we've just gone in to see Sukeshi's mum, who's drinking her milkshake from a cup and doing incredibly well given that she had a stroke last November, such a major one, and looking very comfortable in her luxury bed.

Oh gosh, her hospital bed yes [laughs]!

How about your health concerns? You did mention to me again earlier when we were coming in the car about pain levels in your shoulders and in your back. How has that changed over the years?

In fact, I didn't have shoulder pains and aches up until a few years ago. I've also got neuropathy in the toes and the bottom of my feet as well. I keep getting cramps and pins and needles and sometimes I can't feel the bottom of my legs and I think a study has been done on Thalidomides relating to neuropathy and I think it is ... I don't know if it's proven or not but I think it is Thalidomide as well, lots of us are suffering from it.

With the back, obviously we didn't get any training, or any advice on how to pick up things and some of us have to bend very, very low. If I drop something, I have to get right down on my knees to pick it up and then bend over to pick it up, which isn't the ideal way of treating your back. Lots of us are using our feet to manoeuvre things or pick up things etc.

I'm finding it very difficult because I'm starting to loose ... if I pick up something want to get to it, I find it very hard to balance now as well, on one leg [laughs]. I find it very hard, I need the support of a wall or something like that to then get the thing from my feet. I'm also finding that the lower back is very, very painful, especially when I've been through the day and in the evening at night when I'm about to go to bed, it's excruciatingly painful. I don't like taking pain killers all the time so I try and avoid them as much as possible and just go for the normal, you know, hot water bottle or something like, but that's a short term help. At this stage in our lives, or in my life, I think it's too late to do anything about the back or the shoulders. Again, it's the driving as well that doesn't help. I used to be able to drive two / three hours at a stretch with no problem, but now twenty minutes / half an hour is more than enough before I start getting shoulder pain and back pain. So it's restricted me in travelling as well.

And have you been able to see any medical professionals that maybe specialise in your particular movement difficulties? You know, which parts of your back you're over-using or over-compensating for your arms?

Yes, yes. But the treatment is an on-going treatment which at the moment with my mother in her condition I can't have, I can't spare the time. And although you get the treatment, you are basically still doing the same things. What you need to do is change how you manipulate things or pick up thing. How do we change that?

That would demand an awful lot of work and time that you probably don't have right now.

Yes absolutely and gadgets and everything. When you go out and I drop my handbag, I don't have a gadget to pick it up. Now I have to ask somebody, "Please can you get it for me?" Or I have to bend down and do it myself and that puts your back in trouble as well. So there's not sticks and stones and this and that and the other that you can carry around with you for all sorts of things you know? How many gadgets can you have? You need to carry a suitcase with you!

I interviewed ... it was Geoff actually. He said when he was sent out of, I think it was Roehampton they gave him ... I've forgotten what they call them now, I think it was the bag that you would put arrows in, you know like Robin Hood would. It was like an arrow bag, filled with gadgets, and his mum was saying, "How is he going to carry that around everywhere? How is he going to know which one to get out?"

Exactly! And how is he going to get it out first of all? To get it out, he'd need to drop it on the floor!
[Laughs].

And then look over his shoulder to find the right one.

Well he won't be able to reach it anyway because I know Geoff, even I wouldn't be able to reach it. Sometimes human beings just don't think! [Laughs].

Exactly, yes. And are you working right now?

Yes, I do my own private work. I'm also the chairperson of my local community ladies group so we have about two and half / three thousand members, and I organise programmes for that. We just had one recently on Saturday which went really, really well, I had so many congratulation phone calls it's unbelievable. So I have to organise a programme every month and that's where I'm at at the moment. But three quarters of my time during the day goes with my mum, feeding her, making sure she's okay. Just like you saw just now, if I'm not around she'll start crying.

Yes, yes. The sound of your voice is probably very soothing for her.

It's reassuring to her that I'm around. I don't even sleep in my own bedroom now. I sleep in here on the floor so that I can keep an eye on her at night and I have a baby monitor there so that I can hear her.

That's very dedicated.

She gets up about three or four times a night, so every time she gets up she wants me up as well.

And what does she want from you when she gets up in the night? Just to hear your voice?

Just a cuddle. Just a cuddle as well. Just reassurance. And just to know that I'm here, that I haven't gone anywhere. And it's nothing really major. I give her a cuddle and in two minutes she goes back to sleep again. Or sometimes she needs changing. Her diaper needs changing.

Because she's uncomfortable and she's aware of that.

If the diaper's wet then you don't like ... we don't like leaving her in it either. And it's uncomfortable and might give her a rash and stuff and make it worse for her so.

Gosh, you've really got your work cut out at the moment haven't you?

Yes, yes I have.

And one of my final questions is what are your hopes and wishes for the future? I suppose you're just tied up with the present, aren't you, at the moment?

Yes, I am at the moment. For me at the moment, my goal is to get my mother as well as possible and I don't think about me at the moment. I don't think about my aches and pains, you know, they'll always be there. They're not going to go away that easily. But at the moment my ambition is to get my mum as well as possible, get her a quality of life and then think about me. Because I know all her life she's thought about me and it's about time somebody thought about her as well. It's sad that I have to do it at this stage where she's not well. I wish I could have done it when she was well and taken the load off her mind but your child is always your child, whether they're going to be eighty or ninety or fifty or whatever.

And they still look like a little baby to you I believe, people say. You know, you still see the little child inside of them.

Yes absolutely, yes, and I'm appreciating that now more than I used to. I used to get quite embarrassed when she used to treat me like a little girl or a little baby, you know? But I'm appreciating it more now. And a mother's love ... you never find it anywhere else.

I agree.

Never, never.

Your feelings and thoughts about Thalidomide in general now you're older and now you've probably learnt a lot more about the origins of the drug and you've become more involved in the community. What are your thoughts and feelings now about what happened in your life or about Grünenthal?

I've always claimed to be very angry. I am very angry, they've taken my life away with no remorse, no regret. The apology was just stupid. They might as well have just slapped us all.

I think it was worse than if they'd ... it would have been better for them to say nothing.

Or just slap us all, you know, just stand us in line and slap us all, it would have been as good as that. In fact, it's very demeaning, as well, I think, you know. Apologies after fifty years saying that they were in shock. Our parents are still in shock, you know, we're in shock. You're not in shock, we're in shock. And to say something like that, it's a joke. And I think they've made great fools of themselves. Any sympathy that other people might have had, I hope they haven't had, but any sympathy they may have had, I hope it's gone down the drain.

I've always been angry about it. Psychologically it's affected a lot of thalidomiders, physically, of course, it has. You can see the physical effects but you can't see the psychological ones and it's had a ripple affect, it's affected parents, it's affected families, siblings, grandchildren, children, you know, everybody! It's not just been the thalidomiders, it's been everybody around them as well, you know. I'm not saying I could be a better friend to my friends but I could be much more helpful to my friends if I'd been normal, much more helpful to my parents, my siblings, you know. I'm restricted in what I do and I hate that because you want to do things to support your family and you're only restricted because of physical disability that was caused not by nature, not by an accident, but something that was deliberate and that is very frustrating. It makes me very angry.

Yes, because it need not have been.

It need not have happened. With all the evidence that we have now, with all the evidence that is coming out now that they knew what had happened, they knew how it had affected people, you know, it's incredible that one human being can do that to another human being and not take any responsibility for it. That's the worst bit. Money isn't everything and them giving me money isn't going to give me my life back but money is important because it's going to give us the quality of life that we need.

And also because it's a recognition of the wrong they have done. I mean they obviously can't go back and change the way you were born.

No.

But the only way they can recognise it is actually by giving you money.

To provide. Lots of people say to me, "But you're so wealthy, you've got all the money that you need and why do you need more?" I haven't got insurance for me when I get older. I don't know how old I'm going to get. I don't know how badly I'm going to get affected, you know. Things happen with the snap of a finger. Look at my mum, we didn't know that this was going to happen to her. Tomorrow I might not be able to move at all. I'll need two or three carers twenty four hours a day. Who's going to pay for that? Why should I drain my hard worked money for something that is somebody else's mistake? So, for me, compensation is important, it's very important, it's to secure my future.

I think you're completely right. And ...

[Interruption by PA bringing in drinks 04:22]

So my final question is, is there anything that you think we haven't covered? Is there anything that you feel we should have talked about or that you would have liked to have said more about and I have got in the way?

Not really but I do need to say something. Why do we ... the question for me is ... I've got lots of questions for Grünenthal and if someday I do meet some of them I would like to ask ... the question for me is, why are we having to do this? Why are we having to struggle and fight and campaign and even have to ask for compensation that we deserve? Why aren't they, with their thousands and millions and millions that they are earning, why can't it come from them? "We are sorry and you really deserve this, you really do deserve it." I know there are a lot of us but then that's your products that's caused all of this. So my question to everybody, the whole world, is why is everybody standing by and letting us campaign and letting us fight for what should be rightly ours? The whole world is watching us. Publicity, yes, the newspapers are doing it because they need a story, television is doing it because they need a story, but what about us? We're not stories, we're human beings.

Yes. Well I'm hoping that this project will help to put that side of things across.

Yes. There are only a very few of us who are quite strong. If you'd talked to me about this three or four years ago I would have broken down. I couldn't have had this conversation with you without at least crying a few times. But I've got that anger in me and, actually, this apology has made me even more angry, you know, so it's even made us more determined that we need to get what we deserve, full compensation. And the other factor is that we are adults now, a lot of us that can handle our own finances, a lot of us have gone into businesses, are professionals, at least I don't want to be treated like I can't handle my money. So if I do get compensation I know how to spend it, I know how to look after it as well. So I don't want to be treated like a child where I have to put it in a trust and for me to ask for my money. It's rightly mine, I know we've set up the Trust ourselves, but it's rightly mine and I think I'm capable of taking care of it.

Perhaps that will be something that changes.

I hope so.

Because I can see why it was set up in the first place.

I do as well.

Very important and precisely to stop the abuse of people's money.

Abuse by parents as well, lots of parents have abused it, absolutely, I agree with you. But most of us are coming up to fifty or have been fifty and I think any normal un-disabled person, I know it's not the right word, would be handling their own affairs anyway. So please I'd like to be treated like an adult.

Yes, that is an interesting way of putting it. It's ... if you were given compensation from any kind of an accident, then nobody would be saying, "Yes you can have it but I'll give it you ..."

In stages, yes. Or even if I'd won it in the Lottery, no-one's going to say to me, "Look, you have to put it in trust. I'm not going to give it to you. I'll give you an income every year" but, you know, even if you win the

Lottery at twenty / twenty three, it's yours to do what you want with. And I think most of us thalidomiders know what we're in for and hopefully spend it sensibly [laughs].

I'm absolutely convinced you would.

I'm very tight with my money [laughs]. Very tight. I'm generous but I've learned my lessons so every pound counts, you know.

Sukeshi, thank you ever so much. It's been a fantastic opportunity to speak to you. I'll send you the transcript through.

Okay, thank you.

The idea then is to do a follow up interview which will be much shorter. So you'll look at the transcript and you might say, "Oh yes, I didn't tell her about this, I forgot this" and I'll look at it and I'll think, "I should have asked her a bit more about that." And then we can just cover any areas we think need a little bit more ...

Sure, sure, okay. I just wondered ... we covered topics like personal hygiene and this and that and the other. I just wanted to tell you a little bit more about, you know, how it works. When you're not disabled, when you're a normal person and you're ill or you're having a baby ... like my sister said to me, "Oh, I've had a baby, it doesn't matter, the nurses have seen everything, the doctors have seen everything," that's a one off thing. You never go back to that person and see them again.

Now with me I've had ... what has upset me most about being a thalidomider has been the carers. I've had a change of carers over the years. It's very difficult to, you know, to have your personal things done by different carers. You get very used to one carer. It's very hard in life to keep having new ones to clean your bum, to give you a wash, to do personal things for you. And for normal people to think that's very easy to do, it's quite heart-breaking, it's not ... it's so embarrassing I can't tell you. It's so embarrassing. I'm very used to my carer, she's been with me twenty two years, and you know it's like she's not there because she does everything for me, it's just natural. But if I had somebody else come in and do something for me now I'd be very embarrassed – a) because I feel embarrassed them looking at my hands; b) my body's not perfect again, why should I have to show it to another human being? So that's another factor that normal people ... probably the drug companies ... it's not just about the money, it's about personal things that we go through day in, day out that they never think about.

Well I know when I was in hospital recently with my operation and I had to have help getting clothes up and down and going to the bathroom and I found it, even with nurses who do it every single day, they've seen every single body you can imagine, I still found it embarrassing. I tried to struggle to do it myself rather than asking.

Yes, I do as well.

So I can see where you're coming from.

The other thing is ... it might be psychological or whatever it is, even the nurses, when I've been in hospital, I can't even ask the nurses because I think they're laughing at me because they've seen normal bodies and then all of a sudden they see this thalidomide body. Even though they might be innocently laughing about other things you think, "Oh, I'm not going to ask her because she laughs at me." So that, for me, being a thalidomider has been the worst, not being able to do my personal things.

Yes, yes. I can understand that because you've fought for independence in so many things, found your own way and there's always this one thing ...

Correct. That we can't get independence for. That's why I think we put ourselves into the place where we know we can win, where we can ask for compensation maybe, we can win with that. We can ask for this, that, the other, we can win with that. But there's no way that we can win getting our own independence. That's the one thing that really, really ... I don't know about the other thalidomiders, that's the one thing that really I feel very angry about, very frustrated about.

Well, your thoughts and feelings are recorded.

Thank you [laughs]. Thanks.

Shall we stop there for today?

Yes. Thank you.

Thank you very much.

END OF RECORDING

