Thalidomide: Simone Baker (2012)

Ruth Blue interviews Simone Baker for the *Thalidomide: An Oral History* project.

This is Ruth Blue, interviewing Simone Baker on 26 June 2012 at her home in Reading for Thalidomide: An Oral History. Simone, could you confirm that you've signed the copyright and consent forms?

Yes, I've signed them.

And would you first tell me your full name, the date and place of your birth?

I'm Simone Jill Baker and I was born on the 27 September 1962 here in Reading, Berkshire.

This first set of questions are mostly going to be about your family background, childhood, school life and early medical interventions. So first could you talk a little bit about your family background – who your parents were, what they did and if you had any brothers and sisters?

Okay, I was the oldest of three girls and we were born fairly quickly in succession so there were only three years between myself and my youngest sister. My mum is Andrée Cleveland, or was Andrée Cleveland. Her background was that she was a nurse and she originally came from France. She moved over here when she was a child at the age of eleven. My dad was John Cleveland and he's dead now but he was a sailor, that was his background. So I think they met through family somehow, I'm not quite sure how, but that's their background. My sisters are Michèle and Yvette.

Thank you. And moving on now to think about your parents' decision to use the drug thalidomide. Do you know who prescribed it for your mum?

I'm pretty sure it was her GP.

And do you know what it was prescribed for?

I'm not altogether sure but I think it was either morning sickness or sort of general anxiety.

And do you know how long she took the drug for?

I don't.

At the time she took it, did your parents have any concerns about using a drug during pregnancy?

I don't think they did because at that time it really wasn't generally known that damage could be done to an unborn foetus so they didn't have any concerns. They were just … she was given the tablets and she took them. I think she may have had them given earlier to them and they might have been in a bathroom cabinet. I'm pretty certain that was the case that she didn't take them as soon as they'd been prescribed to them but at a later date when she was perhaps not sleeping because she was pregnant or perhaps was a bit anxious because she was pregnant and my dad reminded her about these tablets that she'd had before and she took them then.

And were there other people around at that time that your mum might have known that were also taking thalidomide?

There weren't other people around that she knew who were taking thalidomide but she did know because it was obviously quite late that I was born. In September '62 she did know, from the newspapers, that babies were being born with disabilities and she did talk to other friends that were pregnant at the time about … "Oh, isn't this awful and wouldn't it be awful if we had one of these babies?" So she knew about thalidomide, it was in the headlines then.

Yes, I can imagine at that point of time, if you knew you'd taken thalidomide and you were starting to see the stories in the press you'd be wondering, wouldn't you?

The thing was, at that time they hadn't made the connection between the drug and the deformities. So the babies were being born and nobody knew what was causing the deformities and that's why my mum was worried, just from the point of view of having a disabled baby. There were all these babies being reported being born all around the country and she was picking up on those newspaper stories. But I don't think she would have thought, "Oh my God, I've taken the drug. I might already be carrying one." It wasn't to that point.

Yes, no, you're right. It took a little while before those two things got connected together. And apart from needing to take thalidomide for possibly anxiety or maybe insomnia, did your mum have a good pregnancy in general?

I think so. She doesn't ever report, you know, that she had a difficult pregnancy. So I think she must have done. I think it was her first pregnancy. Again, I'm not actually sure whether she had any miscarriages but, you know, she was excited. She was a young, newly married woman. She'd been looking forward to having a baby; she was looking forward to having her first baby. It wasn't accidental; it was planned, so she was looking forward to having her baby.

In later years after it all came out about the effects of thalidomide on pregnant women, were you ever able to discuss with your parents about their decision to use thalidomide?

I haven't ever really sat down and had a real heart to heart with my mum because I think, you know … and, again, I'm sure you've heard this from other people that it's obviously something that will cause her stress for the rest of her life, the fact that she took that tablet and that, as a result, I was born disabled and she knows that my life isn't straight forward and it's a bit of a struggle. So I've never actually sat down and sort of spoken to her about it.

But recently, whilst we were having a few issues around things, I wrote her a letter and I put in that letter that, you know, there's lots of things … I'm quite a secretive person and she knows that. She knows that I keep my cards quite close to my chest and I don't talk about thoughts and feelings and I'm quite a practical person so that maybe is part of it … what's the point of talking about how you feel? This is life so get on with it. So in the letter I actually said to her, you know, you do realise that there's lots of things in your life that you should be really proud of because I think my mum is … she doesn't always give herself credit for what she's achieved in her life. So things like she and my dad got divorced so I said you must never think that your marriage was a failure because you had these three girls out of it and Dad was a great dad and it was only really sort of in his later life that he, you know, didn't support her as well as he should have done. And she did a grand job of soldiering through and providing for us all. And I also said, "Don't ever blame yourself for me being born thalidomide because I've had a really good life." And I often say to people if I could go back to live my life again and I could either choose to be able bodied and not know the life I was going to have or go back and know that I'd have the life I've had, I'm quite happy with the life I've had. But there are lots of things, of course, that I'd like to get rid of like pain and … but, you know, as a child all the things that I had to deal with really, I dealt with them and they made me a stronger person. And I think … you know, I'm quite happy with who I am as a person and I think she should know, she should take credit for it. And I don't blame her for taking that tablet, I really don't. It's … any mother would have the same at that time in the same circumstances and, you know, okay, everybody could look at their life and wish it were different. That's just human.

But I'm really happy with my life … maybe that's my personality but I almost wake up every day and say, "I love my life." I quite often say out loud, "I love my life." I love what I'm doing at the moment, I'm really happy. I'm not just saying it to make everyone around me feel happy. That's just me talking quite truthfully.

That's very good. And did your mum, did she respond to your letter?

She never wrote back. I mean she lives just nearby but I think sometimes if you write something down somebody can go back to it and remind themselves what you said. And my mum loves writing letters. She's still quite an insomniac and she quite often writes letters at sort of two and three in the morning. The only time my mum writes letters to me or to my daughter is when she's got something quite nasty to say which I think is a shame because, you know, that again is committed to paper and really when someone reads a written word it hurts more sometimes than when somebody says something nasty or spiteful.

So I think, you know, for her to get a letter from me that actually talked about feelings and thoughts and issues was quite something in itself. And she did sort of respond just to say, "I found your letter really moving and it was a lovely letter." So it did what I wanted it to do which was to just really open up a bit to her. And don't think that matters. People might say, "That's a bit weird, to write to your mum when she lives just down the road and you can go and visit her." But I think sometimes, you know, you can't … you don't have the moment to have that conversation. And if you did they'd think, "What's going on here? Is she going to give me some bad news" or something, you know?
So I think, you know, I am quite a practical person. I thought that was the way to deal with the situation and I still think it was the right way to deal with the situation. And I think, you know, my mum's got that letter and she'll keep it. She keeps all her letters and she might refer back to it in times to come when she's feeling a bit fed up or upset. But I think it did change something between us quite considerably.

I'm sure it meant a lot to her even if she didn't say it. I'm sure it would have meant a lot to her. Moving on now to talk about your birth. Where were you born?

I was born in Battle Hospital which … I think part of the building's still there. It's in Reading and it's, like, the other side of Reading.

Do you know how the birth went for your mum? Was it a straightforward birth?

No, it wasn't. I was a breach baby and she knew that from x-rays before I was born that I was going to be a breach baby. And it was, again, in the times when dads weren't present, they weren't routinely part of the birth process. I think she went into hospital with the idea of having a normal vaginal delivery but that wasn't going to happen, you know, I mean nowadays they wouldn't even consider it really. I think she was given the opportunity to try and have me naturally and she … it was quite a tiring birth, quite a long process, she was totally and utterly exhausted by the time I was born and she was quite out of it on gas and air. So by the time I was born she really wasn't with it at all. She knew she'd had a baby but … I don't know how many hours it was but it was a long and quite traumatic childbirth.

And so do you know when your parents were first aware that you'd been born with any kind of impairment?

Well, certainly it wasn't immediately. My mum, because she was a nurse, she kind of knew what the procedure was and she knew that something wasn't right because I'd been whisked away and she kept saying, "Where's my baby? What's happened to my baby?" And they kept saying, "Well, you must rest, you've had a very long and traumatic childbirth. Just sleep. We'll bring your baby to you later." And she knew by the time it started to be dark that this wasn't normal and that she should have seen me and fed me by now. So she asked … although she asked several people to bring me to her they wouldn't or they made some excuse.

So she … I think she started to think something awful had happened and by the time it got to be night she called the night sister through and she said, "Look, I'm a nurse, I know, you know, I know there's something happening. I just want you to get my baby and bring it to me. I don't … if I get into trouble I shall say that's what I asked to happen, so please just go and get my baby." And I think the night sister … again, I'm sure you'll have heard this story basically gathered me up in a blanket, took me to my mum, deposited me on the bed and disappeared very quickly and just left me like a little parcel on the bed. So my mum unwrapped me and just basically saw for herself that I had no arms and no legs. I don't think anything was said at all to her and my mum was sort of … I think her first reaction was, "Oh, I've had one of those babies." And then she said her next reaction was to sort of systematically look at my arms and my legs and look at what was missing and what I did have and one of the things she said that I thought was really lovely was that she looked at my fingers and thought she's got a finger to wear a ring on if ever she gets married, you know, she's got a finger.

I don't think … until I had my daughter, I don't think I realised how hard that was for her. I think, you know, nothing will ever take away the pain that she went through and probably still goes through. I mean I just think I wish that whole situation had been handled so differently for her. And I just can't … I don't think she's ever been truthful about how she really felt. I think she's just tried to put a brave face on it but it must have been awful, really awful. [SB becomes upset].

Would you like to stop for a minute?

No I'm all right.

Are you sure?

Let’s carry on, yes. I just think it must have been awful. I mean she is … she’s what made me how I am but I don’t, you know, I don’t think you can make yourself something that you really aren’t and that must have just been so hard to deal with.

I think though the way you described it, the way you described how she looked at you and she worked out, you know, what your body was like and she then thought of something positive – she’s got a finger for a ring, shows that she must have had quite a strong resolve to support you.

Well, something else that she’d … I’ve sort of learned since is that she did an article for the National Childbirth Trust. They did … I think it was a fortieth sort of anniversary or fiftieth anniversary, I can’t remember quite what. But it was history of childbirth and it looked at all the different decades and as part of the 1960s they looked at thalidomide and they’d asked her to give her account of what had happened and, again, she said that, you know, she looked at me and she said a little prayer which was, “I’m going to really … this is my baby and I’m going to love her whatever. So if you’re going to take her, please take her now because I’m going to love her.” Which, again, when I read that … I was at my mum’s when I read the article and I didn’t have a clue what she’d said or written. But that had obviously just come out and I’d obviously read it for the first time. So I had some tears then really because I thought, “Oh my God” again, because it gave me some insight into what she went through. And I think … I can’t remember whether I was a mum or not by then. But I think just becoming a mum just makes you so aware of the emotions that go on with having a new child, especially a first, and what devastation there must be to not have a clue that … I mean, nowadays there’s so many warnings that something might be wrong with your baby that, you know, it’s very rare that a baby is born that people don’t know that it’s going to have some sort of problem. And you just imagine having this perfect baby. And it doesn’t matter how sweet and pretty the face is, at the same time, part of you is considering the future life that this baby is going to have.

Absolutely. And could you describe your level of impairment?

I’ve got … my legs are affected. I’ve got both my femurs, or my thigh bones, are shortened by about six inches and both my arms are shortened to elbow length. So what I have, in effect, is what I call a wrist bone. I think I was told that they are wrists rather than elbows and I have just three fingers on each hand and some of those fingers are sort of permanently bent so they’re not really very functional for grip and picking things up. And also I discovered, when I was trying to get pregnant, that I’ve got internal abnormalities too. That I’ve basically only got half a uterus, something called a unicornuate uterus which may or may not have been caused by thalidomide but the likelihood is that it probably was.

Thank you. And after your birth, were your parents given any kind of advice or support by medical professionals or social workers?

None at all. I mean my mum asked, when she was still in the hospital, “What’s caused this and could it be those tablets I took when I was pregnant?” And the doctor just told her to shush, be quiet, “You’ll frighten other mums.” So she was told to shut up and, as far as I know, she was just sent home with me. Nobody asked how she was going to manage or what she’d do or whether the housing was suitable. She just literally was sent home with me and left to get on with it.

Do you know how long you and your mum were in hospital after you were born?

No, I don't. I suppose another part of my birth was my dad's reaction. He got a phone call from the hospital saying you need to come in and he was saying, "What's happened? Is my wife all right?" And they wouldn't answer him, they just said, "You need to come in." So my dad presumed that my mum had died in childbirth, he just thought the worst, and he did come into the hospital and they showed me to him in the sluice room and my dad was just horrified and the conversation he had with my mum was along the lines of … my mum tried to be positive like, you know, well she's beautiful and she has got legs. And my dad said, "Well, legs? She'll never walk on those? How will she walk on those?" So, again, just my mum and my dad being complete opposites. My mum tried to be really positive and my dad sort of being quite negative about the whole thing and quite angry about the whole thing. Again, I think a lot of men just felt it was a sign that there was something wrong with their sperm, something they'd done was wrong and it made them less of a man because they'd not had this perfect offspring.

Your mum saw you before your dad did then?

Yes.

She got to see you in the hospital before your dad?

Yes.

And after you left hospital, when you were back at home, were you offered any follow-up care or were your parents offered any follow-up care at that point?

Not immediately I don't think. I know that I did see a consultant orthopaedic surgeon but that was as a result of … I must have had some follow-up care because when I was four I started to have operations and I think, well, there must have been some reason why I started to have those, you know, someone must have been monitoring how I was doing. I went to baby clinic, my mum took me to a baby clinic so somebody would have been making sure or noticing that I wasn't walking as early as I could have been or what have you. But I don't think anything happened initially other than sort of regular baby checks that anybody would have had.

After birth then you were taken straight home from hospital, you didn't go to any kind of medical institutions?

No.

And do you know how other members of your family reacted to your birth?

I don’t know about immediate family but I know a lot of my mum’s friends wrote to her and said, “Really sorry to hear about it” rather than sort of congratulating her. It’s almost as if she’d lost me because a lot of the letters were sympathising with what had happened to her. I think, you know … I definitely wasn’t hidden away. My mum was just as proud to show me off to everybody as if I’d been born able-bodied. She wasn’t ashamed of me, I think she was determined that she was going to show me off to the world and she was, genuinely, still quite chuffed that she’d had a baby, albeit a baby that had arms and legs that were shortened. I think she quite quickly would have just forgotten about them because a newborn baby is going to need all the care that I needed anyway which is that I couldn’t walk, I couldn’t feed myself because obviously I’m a newborn baby. So she just got on and did the things she had to do to look after me.

So was there an impact on your family’s life or the relationship between your parents following your birth?

I don’t think so. I mean I’ve never been made aware of it, you know, I’m sure that having a baby anyway puts a strain on a young couple. My mum’s mum was quite involved and around a bit when I was younger but I don’t think that was necessarily because my mum needed her help I think it was because … I’m told that I take after my mum’s mum so she was quite interfering and, you know, wanted to be part of everything and didn’t have … she just had my mum and my mum’s sister. So I think she just, you know, used to go between the two of them, interfering and doing things.

Would you describe yourself as having had a happy childhood?

Yes, I think I did. I don’t have any bad memories of childhood. My mum didn’t make me feel ashamed or embarrassed or … I know that she liked … other children used to ask her what was wrong with me and she used to just explain it to them. She didn’t cover up my arms and my legs. She took me to the baby clinic. They said, you know, you can leave her in her clothes if you want to and my mum said, well, “No, I’m going to do what all the other mums do. I’m going to take everything off so she can be weighed.” So she didn’t really want me to be treated any differently and the same with my grandma who was quite keen to spoil me more than my two younger sisters. My mum said, “No, you mustn’t do this. It will cause problems later on. I don’t want her to have any better than them. You must treat them all just the same.” And I think she went on to have my middle sister quite quickly which was probably a good thing because she really didn’t have time to dwell on me and my problems. She just had another new baby to look after. And then my baby sister, who I think was unplanned, arrived, again, quite quickly. So my mum really had her hands full with three of us under three years old. So I don’t think she had any time to mollycoddle me or fuss over me. She just had a young family to look after all of a sudden.

Do you know at which point your parents became aware that your impairment had been caused by thalidomide?

I don’t know the exact point but I do know they did get quite involved with the Thalidomide Society once it was set up and went to meetings. I know that Peter Carter, who’s Susan Carter’s, Sue Kent’s, dad lived in Reading as well at that time. So I know that, certainly when I was young … well, they must have been involved with them from quite an early time because Sue Carter’s mum was quite instrumental in making sure that my mum was re-homed from a tower block, where we lived in Reading, to a council house. Saying you should be able to get somewhere more suitable if the lift wasn’t working in the flats then my mum had to carry three of us up lots of flights of stairs to the eleventh floor. So I think certainly they were in touch with other parents quite early on.

So did they ever talk to you about how they felt when they realised thalidomide had caused your impairment?

No. I don't think I ever remember any conversation.

And in the early years of your life when did you first start having any hospital care or medical interventions? What age would you have been?

About four years old. And, again, I'm not altogether sure even now why I had the operations I had. I wasn't … people didn't try and cut anything off or … actually I did have an extra toe when I was born on top of my foot, like a monkey toe. It wasn't a properly formed digit; I don't think it had any bone in it. But that was amputated soon after I was born because it was stopping me from wearing anything on my feet.

But when I was about four I had an operation to straighten my femur, my right femur, because it was growing quite bowed and I think they were quite concerned that my leg length would be shorter that side or something. I don't really know why. But basically they did a bone graft, took part of my shin bone and transplanted it into my femur and attached it with screws to try and straighten out the worst bowed part of my femur because in most people it would be a fairly straight bone. I think one of mine was fairly straight, the other one was a bit bowed, so they made an attempt to try and straighten that to make walking a bit better for me and as to whether or not it, you know, I'd have been better without it I really don't know. But I think neither did they really, it was experimental.

And do you know how long you were in hospital for when you had that operation?

It was a long time I think. I don't know how long but I know that my mum found it really hard because visiting times were quite short. She had two other little babies to look after, I was only four, so my sisters would have been two and one and children weren't allowed to visit and my mum would have had to get a couple of buses across town to the hospital and make alternative provision for my two sisters and I think, you know, visiting was an hour only or something. So my poor mum used to have to do all that in order to come and see me for an hour but, you know, she did do it.

Do you remember that, being in hospital when you were four?

Yes, I do. I remember the sort of metal cot beds and I can remember I had a plaster cast that went right from underneath my arms all the way down at least one of my legs. It went all the way down to my ankle on at least one of my legs. And I can remember finding it quite confusing when I came out of the operation. They laid you on a plastic sheet because the plaster was still drying out, it was still very wet, and thinking, "Well, that must be for me to go to the toilet on" because nobody told me what it was for so I just did a poo I think. They threw the covers back and were, like, 'Oh my God," but I thought that's what it was there for.

So I do have memories from that time in hospital, just being in the children's ward. I remember … I don't know whether it was that time or another time but I can remember seeing my mum go and feeling really sad that my mum was leaving me in hospital because I didn't really understand what I was there for and why I had to be separated and why I couldn't see my sisters. So I do remember those times.

And what were the medical staff like? Did you get a lot of attention when you were on the ward or was it very busy?

Well, I had … I was in hospital twice when I was young, once when I was four, and I don't really remember details of that. And another time, later on when I was nine, when basically they were doing something similar with my right leg, another bone graft, and because of the age I was, I was getting education in hospital then. So that's another sign that I think I was in for a very long time. I don't remember … I remember being very well looked after but I don't remember specifically getting treated any better or any worse than anybody else. But I was there … I used to see other children coming and going and think, "How come I'm still here?" And I can remember watching lots of Norman Wisdom on television because we didn't have a television at home. So I can remember absolutely loving watching Norman Wisdom films on the television which was great because it was something I'd not been used to at home.

So you didn't have a television at home?

No. Not until … I had my first telly when I was eighteen. Bit hard to believe in this day and age. I think we had one when I was very young and I think that broke down and my parents just either couldn't afford to or just didn't bother replacing it. I think my dad always makes out that he … it was a decision he took that television was damaging for us or something but I don't know if that was the truth or he just couldn't afford one really. But we certainly didn't miss having a television at all.

A lot of people these days are choosing not to have one, aren't they?

Yes. Well, I don't watch it really now.

That's possibly because you got used to growing up not having it on all the time.

I just think that they're a complete waste of time. You sit watching a load of rubbish … I mean if I've chosen to watch something … that's why I like to have a television in the house and my daughter, you know, definitely wouldn't allow me not to have one. So … but I think it's a lot of rubbish.

When you went into hospital for the second operation when you were nine … I know you said that you weren't … when you were four you weren't really sure what you were there for, why this was happening. By the time you were nine, did you have a greater awareness of what you were in hospital for and what the operation was about?

Not really. I just knew that I was having an operation on my leg. I mean by the time I was nine I was properly walking. When I was four I think I was getting around but I think they must have got the impression that I wasn't walking as well as I could walk maybe. When I was nine I don't know whether I was getting pain, I don't remember pain. I don't really know why I had the second operation. It wasn't a bone graft again but I think there was some sort of attempt to straighten a bone in my hip.

The second time around it all went a bit disastrously wrong because my mum … I was sent home again with this great plaster cast on which weighed a ton because it was good old fashioned plaster of Paris and I was basically in a lying down position so the only way I could be sat up was to prop me up with lots of cushions and things. My dad actually made me a special chair that I could sit in just so I could be upright. But my poor mum would have to lug me around and I was a nine year old child with this sort of plaster cast on. It had like a bar between my legs which could act as a grab handle but, you know, it wasn't easy for her. When I was younger she had the pushchair but when I was older she didn't have a … I think I did have wheelchair but, you know, it was much harder work.

And do you remember if you were, say, going out with that kind of plaster cast on, do you remember what kind of reactions people gave to you at that time?

I don't … I just realised I didn't quite finish the story earlier on. [Phone rings] I suppose I ought to stop talking when all this is going on, should I? I won't answer it.

It won't pick up particularly because the microphone is connected to you.

So it's all right to talk with it in the background. It will probably be … I probably want to listen to who it is now.

Shall I pause a second?

Yes.

So you were going to finish …

Basically with the second operation once the stitches had to come out of the wound, they cut a little hole in the plaster to take the stitches out. What they didn't realise they'd done was I had two sort of wounds, one at the front of my hip and one at the back of my hip and they took the ones out at the back of my hip but they didn't have a note that there were stitches at the front of my hip as well. So after a few weeks I was smelling really nasty and my mum knew that this smell wasn't right and they just said it's just the plaster because there was a hole cut in it for me to go to the toilet, you know, the plaster's just soiled. But my mum said, "No, sorry but this is really not a nice smell. You're going to have to change her plaster" which they agreed to do reluctantly. But when they took the plaster cast off they discovered this really infected disgusting wound with all the wound dressing just growing into the flesh basically. So they had to cut all that out and clean it all out. And, as a result, they couldn't put me back in a plaster cast so I basically had to go into hospital for complete bed rest and I've got a feeling it was weeks and weeks because it was whilst my leg was healing and the wound was healing and it needed to be dressed every day so I was in hospital a lot longer than I needed to be as a result of that and then they decided to make me like a plastic splint that they fitted in place of the plaster so that could be taken on and off to help my mum with cleaning me. So that was sort of an addendum to my second operation.

That must have been quite painful for you at the time.

Yes. Again, I don't remember it. Obviously the mind has a very good way of making you forget pain. I can't remember … about taking me out in my plaster cast. I don't think my mum could practically take me out. I don't think she could. But I do remember going to visit school in my wheelchair, either in my splint or in my plaster cast and the kids being obviously in awe of a wheelchair and all wanting to take it in turns to push me around the playground. And my mum said she got quite worried because they were running across the playground with me in this full length plaster cast in a wheelchair.

And I do remember going to the dentist who was up about three flights of stairs and my poor mum who was … if I remember, the dentist had to carry me down. So I can only think there was a filling I needed doing or something because I don't think I was easily transportable at that time in my life. She took me everywhere on a basis where I really had to be somewhere rather than just being out socially. I don't think we did do anything …

Were your parents aware of … or did they encounter any kind of disability prejudices around that time, those early years, that you know of?

Well, I went to a special school from the age of four and when we moved house my sisters moved school and my mum was quite keen for me to go to the same school as my two sisters so she met quite a lot of resistance to that. School changed but she couldn't understand because she knew how I coped at home in a house with stairs and, you know, running around with my two sisters. So she couldn't understand why I had to be in this special school at all. And they said, "No, you're doing the wrong thing if you take her out of here," you know. "We need to make sure she's properly looked after" and my mum had a real battle to get me out of that school and into a regular primary school. I think from both ends, I think from the point of view of the school I was trying to leave not letting me escape and from the school she was trying to get me into being quite reluctant to take me and actually when I did eventually move schools to that school one teacher didn't want me in her class, quite honestly, because there was a terrapin building and she said, "I can't have her in this class because there are stairs up to the door." Well, I lived in a house where there was a flight of stairs that I would go up and down all day in the course of playing and going up to bed. So that really wasn't an excuse and as a result of that I joined the class above me where there was one of my friends, my mum's friend's children who was in the class who was assigned to help me if I needed help to go to the toilet or what have you.

But I think also the school took on a member of staff to specifically help me if I needed to go to the toilet. And that woman's still alive and I've seen her quite recently and she said, "You didn't need me. I was redundant really as soon as I'd started." She's still involved with the primary school and, you know, it's a bit of a sort of … I think I went recently to a do they held for her. She's still there as a school dinner lady, I mean she must be probably in her eighties or nineties, she's still quite able and, you know, everybody was reminded how her involvement with the school began. I think she had children that went there as well but it was as a result of agreeing to come along and help me when I needed help to go to the toilet. But I think probably, when I was at the school, they realised that I was fine. I was doing everything that all the other children were doing. Probably causing a bit more trouble than the other children because all of a sudden I had the ability to do my own thing whereas at the special school everything was kind of controlled and contrived and so, you know, I had to go to lunch early because they didn't want me to be knocked over in the rush. Well, that isn't what life is like, you know. Life doesn't stand still and let you go ahead.

It was a good thing to move me because all of a sudden I was, you know, I was ridiculed, I was teased. But I learned how to deal with it from that very early age and I did deal with it. I didn't allow myself to be bullied and not in a confrontational way. I just basically … if children laughed at me I would laugh at them. If they said to me, "Oh, you walk funny, you walk like this." I'd go, "No, no, you're doing it wrong. This is how I walk." And I'd put it on even more. Or sometimes when I stopped walking I would crouch into a sitting position like how you see little children do. And people would be fascinated, "How can you sit like that? How can you … what you sitting on?" And I was sitting on the back of my legs and it was really comfortable to do that. But they didn't understand how I was managing to assume this really unnatural position so I'd wait for them to ask me the question and I'd say, "Can't you see? It's an invisible stool." And I'd stand up and I'd make out I was folding up this little invisible stool and walk off and you'd see them sort of looking really puzzled behind me, like, "How on earth did she do that? Was it really an invisible stool?"

But, you know, I was part of normal school life then. I was part of … the special school, really, was quite damaging to me because I was being taught with children with quite severe learning disabilities and emotional problems, you know. They were acting very abnormally but between the age of four and seven those children were, in my eyes, normal. Because that's all I knew. So I had to deal quite routinely with children having great big plaster casts with holes cut in them which looked, to my young mind, like the hole that just went inside of them, you know, with all Gentian violet spread over the holes and children that were funny shapes and children that walked funny and said funny things.

And one boy who used to take a big group of us after lunch down to some woods that were at the bottom of the playing fields and defecate and, being young, you're interested in those sorts of things and I just didn't think anything of it. I thought that was quite normal. And I mentioned it to my mum and dad one day and they said, "Oh no, you must tell somebody that he's doing that. That's not right. That's not good." And I was, like, "Okay." But I'd come home and I'd make little Plasticine models of people in callipers and wheelchairs and I'd do operations on them with pairs of scissors and take bits of their body out and my sisters … they thought this was fantastic and they both copied me. So my mum would quite often find these little Plasticine people with callipers or walking sticks or in wheelchairs. And I think that's partly why she wanted to get me out of the school She understood that my whole idea of the world was being moulded on what I was seeing at school.

Another episode that really sticks in my mind is that we used to get picked up by a minibus that was called an ambulance, a school ambulance. It wasn't an ambulance it was the school minibus. But just calling it the ambulance and it used to come round to the estate where I lived which is pretty close to the school, pick us all up, and we stopped off to pick up this one boy and we got out and his mum came to the door and then he came back and I don't know whether he told us or whether he found out but basically he'd just died in the night. And, again, no kind of counselling or explanation given to this young group of children. You just had to deal with the fact that one of your school mates who was in the minibus had just died overnight which was just … I don't remember it having a devastating effect on me thinking that I was going to die. I just remember dealing with it and thinking that was what school life was all about.

Things like they used to see if your feet touched the ground from your seat and if your feet didn't touch the ground they'd make you a little sort of raised up board with a little piece of carpet on the top for you to put your feet on and I remember thinking, "I want one of those." So you'd recognise this woman who came around to have a look and eye up all the class and see whether anybody's feet didn't touch the ground. And I can remember holding my feet up and her deciding that I was going to get one of these boards. "Oh I'm going to get one at last, at last!"

So I don’t … I do remember things so vividly from that time of my life but I obviously was being affected by my environment. I remember doing … I must have been about five or six, doing a load of sums and when I moved up from the nursery into the sort of main part of the school …

Was this still the special school?

Still the special school. Taking it up to the teacher and she put a lot of ticks next to the sums and crosses. So the next sums I did I put ticks next to the sums because I thought that was what I was supposed to do and she said, “Oh, no, no. I put those on there to show you which ones are right and which ones are wrong.” But not understanding that that was what they were about.

And I can remember, later it must have been, when I was at the school hearing somebody leaving and it must have been some sort of leaver’s event and the headmaster congratulating them on sort of having got an O-level or a GCSE and thinking that’s what I want to get. It really wasn’t anything much that they’d achieved and that would have been me really if I’d stayed there because my parents were led to believe that I was a really bright young thing and would go far. But actually I was just average. I mean, compared to a lot of my peers in the school I was above average because they had learning difficulties and health issues and were in and out of hospital and I was just learning and quite normal really.

How did you find that transition from a special school like that to going into a mainstream school?

Well, as I think I’ve already alluded to, I think I had a bit of freedom. Nobody was keeping an eye on me. There wasn’t so much routine, I was walking to school with my sisters. I think I was allowed to ride my bike to school and I had a little electric car that the Thalidomide Trust were giving to people and I’d take that to school sometimes. I wasn’t allowed to take it into the playground but I’d park it somewhere outside the school and, again, most children weren’t allowed to take bikes to school but because it helped me with the journey … it was only a short journey, I mean, not even half a mile, but it helped me get there. I had my bike and I was allowed to park it and the other kids thought that was … they were quite jealous of it. And the fact I had a bike at that age … it was a bike with stabilisers.

But I don’t remember it being hard or difficult. I think, you know, and I don’t remember … I think because I joined the school quite late I was probably made quite a fuss of. There was one girl who, on the first day, she decided she was going to look after me and took me under her wing. She was like an overweight, ginger-haired child so I think she kind of knew what it was like to be excluded so she made up her mind I wasn’t going to be and we actually were best friends all the way through primary school. A girl called Wendy. And she really did look after me, things like she would give me an aeroplane ride in the playground which was, you know, grabbing my arms and lifting me up off the ground and spinning around with me and would accidentally let go of me and I kind of spinned across the playground on my face. And then part of her looking after me would be to take me to the first aid room and get me all patched up. But I didn’t blame her for it, it was just part of having fun. And she was quite a caring person; she did look after me and make sure I was okay.

What were your favourite subjects at school?

When I was at the special school it was pottery. We used to do pottery once a week and I used to love doing that. And I don’t … I just remember hating maths. I don’t think I had a particular subject that I liked more than others. I quite enjoyed drawing and art; I think that runs in the family. We're all quite arty and artistic, we like drawing and painting. I don't remember any one lesson.

I mean I hated P.E., I mean not because it was difficult, I just didn't like the physical … actually it was difficult. Even at primary school when you were told you're going to make an arch now, you know, we're going to make an arch. It was something I couldn't do or getting onto or off the floor was quite difficult so those were the times when I was reminded of my differences and I didn't like that. It wasn't anything to do with being teased; it just reminded me that my arms were short or that I couldn't run as fast. Things like the sports day at secondary school … oh gosh, you know, long jump and high jump. They made me do all of these things which was probably quite a good thing but I knew it was going to be … I knew I was never going to get over the high jump and the fact that they lowered it very low was just demeaning. And the fact that they made me run the hundred metres knowing that I'd still be running the hundred metres after all the other kids had run was awful. But at the same time it gave me the experience rather than just sitting everything out and watching, I was part of it so at secondary school I played tennis, I played rounders. I threw a javelin, I threw a discus. I'm sure I remember doing badminton and gym. My poor partners were … in badminton and tennis spent all their time running after shuttlecocks and balls because if ever I hit them I never returned them. But I never remember anyone saying, "I don't want to be your partner."

And, again, I remember picking teams and, again, I know I'm not alone in this but all the fat, ugly un-sporty ones were the ones that were left to the end and now, thankfully, they understand the damage that does to a child, of them being continuously being the last to be picked. But I don't remember being that bothered by it but I know it would have been really nice to have been picked first. But, of course, the team leaders were always the ones that were the sporty ones, good at sports, and they didn't want someone who couldn't hit a rounders ball in their team.

Yes. And you mentioned there was a bit of teasing going on at school and you fended that off by making jokes about things. Was that a big feature of school for you, people pointing out your impairments? Or was it just a sort of background thing?

Just a sort of background thing. They got bored because I didn't react to it particularly. They like a reaction, bullies, they like someone who's going to cry or get embarrassed. But I could give as good as I got so they soon learned to go elsewhere if they wanted to pick on somebody. I mean my dad sort of said to me, "If anyone hits you, just put your head down and head butt them." But I never had to do that. I never had any problems with physical or mental bullying to any great degree.

And when I went to the primary school, for a short time I actually became a bully because I think I discovered this power that I had. And there was an incident where there was an overweight girl and I took her bag and put it in the boy's toilets and she was crying, she wouldn't go in there to take it out but I'd put it in there. I thought it was a bit silly really and everyone was laughing. I said, "Well go in there and get it if you want to" and she was crying. And then the bell rang and we were all sent to our classrooms and the headmaster came in and said, "Does anybody know who put Diane's bag in the boy's toilets?" And we all said, "No, sir.' And then he went into the next door class and said, "Does anybody know who put Diane's bag into the toilets?" And my sister put her hand up and said, "Yes, that was my sister." So the headmaster came and hoiked me out of the class and I got in trouble for that. But I think I'm not proud of it but I was just finding my own feet and discovering that I could do that too. That was the only incident that I can remember being particularly obnoxious and horrible.

I was going to ask you about secondary school education. Presumably you went onto a mainstream school, not a special school?

No.

And I was going to ask you next to tell me a little bit about how you got on at secondary school, did they make any changes to accommodate your impairment whilst you were at secondary school? You mentioned you had somebody to help you at primary school.

My best friend at primary school, Wendy, when we moved to secondary school, we asked whether or not … my parents were involved as well. We asked whether or not we could be in the same class because I needed her to help me. I don't think I actually did, I just needed her to look out for me and she was my best friend and I wanted her in my class and ended up in the same class. But very soon after we started secondary school we just went our separate ways and made different friends and the school … I don't remember, again, until much later they didn't make any provision for me.

I mean it was a massive school, it was a huge school, it was widely spread out and lunchtime was never long enough and we used to have to get the whole length of the school to get to the lunch hall. And once you got to the lunch hall you used to have to stand in a great big long queue and I used to have to stand in that queue even though it was hard for me. And then you used to have about ten minutes to eat your lunch which was gobble, gobble, gobble and then you used to have to run back to your lessons because there wasn't long enough to have a leisurely lunch and my two friends used to get really … they never left me behind. They used to get very frustrated because I'd be slower than them and they could run and I couldn't so they used to grab my arms, one each, and run with me and my feet would be basically hardly touching the ground and we used to think it was quite funny but, you know, I was literally flying through the air just to get back to lessons on time.

But I never had any extra time in writing exams or … the only tine I had extra help was doing my O-level cookery. They didn't want me to do O-level cookery but I said, "I want to. Why shouldn't I?" And they agreed I'd have somebody to help me do all my washing up which ended up being my sister, I'm not quite sure why but maybe she knew what help I needed. And I never really was talked out of doing anything I wanted to do because people felt I couldn't do it and my mum was always quite supportive, that if I wanted to do cookery and the school put up objection, she'd be there supporting my wish to do that and saying, you know, "Why not? She cooks at home, why shouldn't she do this at school?"

And, again, it was a bit the same with … when I went on to leave school. I decided to stay on and do a secretarial course. I'd got a typewriter at home, I'd been using an electric typewriter and I'd been typing things and all of a sudden here they were saying, "Well, she won't be able to use a typewriter" which I don't think I'd have been able to as it was manual typewriters then. But they had one golf ball machine so I think I just about chose the right time to do that. I had the golf ball machine and I was allowed to use that whilst everybody had to use a manual typewriter and, again, it wasn't really an issue. I think they just probably accommodated me. They saw that I didn't let things stand in my way and just accommodated me doing whatever I was doing.

I had a taxi getting me to and from school which was the other thing I suppose. We lived about probably two and a half miles from the school which was far too far for me to walk. It was just about possible. I did do it once or twice when the taxi forgot me or something but I used to get picked up by taxi and go into secondary school and collected by taxi. My poor sisters weren't allowed to go in the taxi because the taxi wasn't for them. So it if was pouring with rain, they'd still have to walk or cycle whilst I got picked up in my nice Volvo or whatever posh car it was and taken to school. I mean occasionally I think the taxi drivers would let them nip into the car on the way back but most of the time my sisters were quite happy to walk with their friends or cycle with their friends.

But, again, you don't realise at the time it's quite isolating because the journey to and from school is time when you get to sort of be mischievous and be with your friends and I was probably a bit of a little angel at that time because I didn't get the opportunities at that time to be naughty that my sisters got.

And when you were nearing the end of secondary school, you mentioned typing. Did you have any other kind of aspirations or ideas about careers that you'd like to go into or areas you particularly felt drawn to?

My dad wanted me to go to I think … is it Lord Treloar College? It's a school for disabled children or a college. And he started to get all sorts of brochures for different residential places and I really didn't want to do that. I really didn't. And I couldn't understand why my dad was even considering it because to me it felt, well, why does he want to get rid of me? I think my dad wanted to do it because he was already planning what I should do with my life and he wanted the best for me, as anyone would for their children. And I don't know if he … that might have been earlier. That might have been when I was still at school and enjoying school. But I didn't want to move. I didn't want to leave my friends behind and my sisters and my family and my house. And the idea of staying away somewhere was just horrible. I really wouldn't have wanted that. I know that he looked at it but there wouldn't have been any pressure on me. So I don't know whether he was just looking at different options.

But in terms of, say, a job or a career – some girls wanted to become a nurse, do you know if you had a …

All the things I wanted to do were really ridiculous like I wanted to be one of Pan's People, you know. I used to think, "I want to do that." I don't remember having any other plans to do anything else and I really didn't have any … even when I did the secretarial course, it wasn't with a view to being a secretary. I thought that will be quite a useful skill to have and it will get me into most places.

A lot of my friends stayed on to do A-levels but, again, I don't think I really wanted to go to university. I don't think I wanted to be away from home. I liked being at home, I liked being around my family and I wasn't … I didn't look at that … I'm sure I could have gone to university, I'm sure I could have done A-levels but it just wasn't something I wanted to do. I just wanted to get out into the wide world and show everybody that I could just do whatever I did, you know. I don't think … I just wanted to start earning money and going out to work. So the secretarial thing wasn't what I planned to do, it's what I ended up doing just because that's how I was qualified and that was the work I was looking to do.

Going back just a little bit to … you mentioned earlier about your parents becoming involved with the Thalidomide Society. Do you know if they were involved at all in any of the campaigns for compensation?

Yes, my dad most certainly was. My mum really couldn't understand why he was getting as involved as he did but I think my dad was always a bit more out for the money and the compensation than my mum was. My mum was kind of like, well, you know, "This is my life now. This is my child and just get on with life." And because she had my two sisters she didn't really have the time or the energy. She probably would have had the ability but she didn't believe enough in her own ability to be a campaigner and a fighter. I think she's quite a peaceful person and gets on with things whereas I think my dad, probably a couple of ca-ching pound signs popped up in his eyes and he thought, “Here’s a chance for us to get some money without, you know, for the family without me doing very much.”

And I think that was my dad, really, because my dad was quite eager to make a lot of money without doing very much and most of the ideas he had to make money happened at the wrong time. For example, he decided to set up a shop selling scooters and repairing scooters but after the main scooter period had happened. So he was never going to be a millionaire that way. And later on in life I remember him having a sideline of plates you put a photograph on and glazed in a little oven and he bought all the kit but, again, that never made him any money. So I think he was always a bit of a schemer, a bit of a gambler, probably. He did Spot the Ball, he played the fruit machine and I think my dad just had ideas that he’d just win all this money and be happy ever after. So I probably fitted in quite well with his personality and how he was. “Oh here’s a way that we can have that money and it won’t be too difficult but we need to fight for it” so my dad certainly was part of the … he was one of the parents that fought on for the additional compensation.

When you were a child, were you aware that those things were going on? Did your parents tell you about the compensation and that your impairment had been caused by thalidomide?

I don’t think they hid it from me and I remember this man coming to meet with my dad quite a lot who … I don’t know whether it was to do with the compensation or whether it was later and it was to do with the bank and how my money would be put in trust for me. But I remember, you know, people coming to the house and I knew it was something to do with me and I remember my dad having sort of piles of letters that I knew were about me but I wasn’t really interested in it to be honest. I wasn’t … I didn’t understand money at that time. I was probably seven years old so it was just going on in the background. There probably were discussions about it but it didn’t involve me, it was just above my head really.

So what age do you think you were when you first understood that your impairment had been caused by thalidomide?

I really don’t know the answer to that one. I think I always grew up knowing that, like the same way … when were you given sex education? It came in dribs and drabs. It wasn’t just like, “Right, we want to sit down and tell you about why you’re disabled.” It was just fed to me in little dribs and drabs and questions were answered so that I always grew up knowing that my disability had been caused by a tablet that my mum had taken but I don’t think, you know, it ever was like … there ever was a dawning moment where bam suddenly it hit me.

Did your parents attend any of the events and meetings organised by the Thalidomide Society or any other groups?

Yes, I think they did. And I don’t remember much of those. The things I do remember is that there was a social worker who worked for the Trust called … I can’t remember her name now, it will probably come to me in a bit. But she lived in Slough and she visited, you know, people in this area. So she used to come and visit with my mum and find out how she was doing, if there was anything she needed. Mrs Ramsay her name was, Lillian Ramsey, and as part of what she did, she used to organise a Carol service at Christmas in Stoke Poges near Slough and all the ladies of the village would make a nice tea for everybody afterwards. There was lots of other disabled children, not just me. And there’ll be a Father Christmas who gave out presents and I just remember they were fantastic parties. We’d have … I’d go with my sisters and we'd all have party dresses and we'd all be made a fuss of and all the old ladies would say, "Hasn't she grown?" You know, the Carol service, you had to go to that, you didn't particularly enjoy it but then you'd look forward to the bit afterwards which was this really nice tea and Father Christmas giving out presents. They were all things that had been donated or made and as you got a bit older you started to get a bit fed up of these presents because they were all second hand – brooches or bracelets or knitted toys. You were, like, "Oh, lovely, thank you." But, you know, actually they weren't that exciting but the parties were really good.

And at those parties, would you have met other children who'd been affected by thalidomide?

I think there were other children there. I don't remember who they were but I'm pretty sure there were other children. Not a great number of them but …

So do you think there was any kind of peer support going on with your parents with other parents of thalidomide children?

They definitely got a lot of support from Sue Carter's family, or Sue Kent, she was Carter. Things like … they were a better off family so I got all her cast off bicycles that had been adapted with longer handlebars which I was really chuffed about. And we used to go and visit them for tea. I don't remember them coming to our house and I don't … I think, you know, we'd just go and play with their children and the adults would just talk. So there was peer support going on. That's the only bit I really remember. I'm sure they did go to Thalidomide Society meetings in London. I know they did but I don't remember if I went with them. I don't remember … I think I probably did go with them but it was boring and uninteresting and I probably didn't understand why I was there.

At any point were you offered any kind of prosthetic aids or encouraged to try out prosthetic arms, for instance, or when did you get your first wheelchair? What kind of gadgets and technology helped you? What were you offered in the early years?

I didn't get offered prosthetic arms or legs. When I was very little they made a couple of little splints, this was when I was a baby, to try and straighten out my arms because my arms were curled underneath my armpits. They decided that to try and straighten them and bring them round to the front would be a good idea. So my mum had all these splints that she kept for a long time. She hasn't got them any more I don't think, but I wouldn't put it past her. But she used to have to put them on me every day and do little sort of arm stretching exercises with me.

And then when I got a bit older I used to go to the Mary Marlborough Centre at Oxford which was part of … it's part of the Nuffield group now and I was there for quite a long time. I know other thalidomide people that went there. But you'd go there and stay for a couple of nights and, again, I hated it because it was hospital and I was away from home and I was taken there and left there and I was surrounded by adults who would ask me how I combed my hair and they'd make me little gadgets to try and help me. So a bit of broomstick with a hole drilled in it and a long handled comb to do my hair with, elastic shoe laces. They made me … I called them egg cups, little suede covers for my elbows because when I fell I'd completely take all the skin off my elbows. So they made me these little egg cups designed to protect my elbows. But, of course, I didn't put them on every day so the chances of me falling over when I actually had them on was really remote. And I'd come home with this big suitcase full of bits and bobs that my sisters and I would all look at and get quite excited about. But I soon discovered that the thing that was supposed to help me put my socks on wasn't half as fast as getting one of my sisters to do it and it used to stretch my socks so they would fall off again and the special school I was at as well took an interest in the things I was being given to help me be more independent.

So things like … what are those things that you have a sort of plastic handle with a sponge in to wash the dishes. They gave me that and bent it and they said, "You could put a bit of toilet roll in that and use it to wipe your bum" and I was kind of like, "I don't want to carry that around with me." And at special school I remember them saying, "Show us this gadget and show us how it works" and they didn't actually mean I should go to the toilet they wanted me to just show them how I'd use it. But I can remember all these teachers stood at the entrance to the toilet and me thinking, "I don't really … this is a private thing, I really don't want to show them all." I wasn't expected to strip off or anything but I was like, "I don't want to show them my bottom wiper, I really don't."

So I had a few visits to there.

And were any of the gadgets that you brought home … did any of them end up being something you found it very hard to live without? Did any of them become necessary?

I had a stick that I could use to pull my trousers down with and my pants down with and that I did use. I mean I had a helping hand which was around. It didn't get used very often but it was something I used in an emergency to reach things or pick things up off the floor.

What's a helping hand?

It's sort of like a grabber, an extended grabber. There's a trigger on one end, it folds and it's got pinchers on the other end and you can pick things up off the floor. Everything else I think I just left by the wayside. I probably think the long-handled comb was a good idea but after a while I realised that I could just comb my hair with a long-handled comb if I leaned my arm on something. So I didn't bother with the pole attachment. I don't remember anything else. That was about all, the dressing stick.

You mentioned a little car though. You had a little electric car that you used to drive to primary school.

Yes, I had … I think, again, part of the … I think it was to do with the Trust and I know that there was some footage shown at the fiftieth anniversary … so I had one of those little cars. And, of course, they were great because … well, they were to a point because you could get around but I could walk, that's the thing. I could walk but I couldn't walk very far and it was tiring for me. So I would basically hold the family up. But with this little car it was just a nightmare really because it didn't go that far before it ran out of battery and my sisters would have to both push me all the way home which they weren't very happy about. But for a while … I mean the first one I had I must have been about six or seven and, of course, all the kids in the neighbourhood were really jealous. It was like a little bumper car and they'd all want a go in it. So that was all it bought me, a bit of street cred really, it didn't really buy me much mobility. It was quite impractical. I can remember driving up and down the road outside my house on it. So it was a toy really. Because I could walk it wasn't a mobility aid, it wasn't the same as for some people who would otherwise not be able to get about at all. It was just a bit of fun for me.

Do you know what happened to it, the car?

I don't remember. I had two of them. I had a little red one first and then I had a bigger blue one. I don't remember what happened to it.

And apart from those … you mentioned those two operations, one on your leg and one on your hip, and going in to Nuffield Orthopaedic Hospital for help with prosthetics, did you have any other on-going health problems or medical interventions during this period of time, up to the end of secondary school?

No, I think that was all.

Is there anything else that you'd like to add about your life up to this point, to the end of secondary school time that you think we haven't covered or that feels very important?

No, I just think my family were, you know, still are a great family and I had some fantastic opportunities as a child that I wouldn't have missed for the world. My dad used to be into camping and we'd pack up this massive old frame tent in this old banger of a car and we'd each have a little box that we'd take clothes in which was basically the only way my dad could fit everything in the car. We'd be limited to what we could take and we'd go off to France in the car because my mum was French. My dad couldn't speak hardly any French, he'd think he could but he couldn't really. All he knew was *comme ci, comme ça* and *merci* and *grand bier*. He knew an odd word.

Bonjour.

Yes, things like that. But in his mind I think because my mum was with him we'd have things like holidays in France and we'd basically just drive until we found somewhere we'd like to stay and he found a farm and my mum would be given the job of saying to the farmer in French, "Can we pitch up our tent in your field and we'll give you a few Francs in return." So they were brilliant holidays because they were … and we went to brilliant places. We went to Lundy Island which … very few people have been to Lundy Island, a tiny little lump of granite just off of … I can't remember where it is. Is it Ilfracombe in North Devon? I think it is. But my dad would have these whacky ideas and my mum would go along with them and when I think back I think, "My God." Taking three little kids, one of whom was quite severely disabled and had mobility problems and needed a lot of help, couldn't manage to go to the toilet on her own, off to a farmer's field in the middle of nowhere or off to this lump of granite in the middle of the North Sea is quite something but that's how they were.

We did a lot together as a family. I always remember lots of things we did, we'd go off to pick primroses, I don't think you're allowed to pick them any more. But we'd go off to pick primroses in this wood and my dad would call it Pogles wood, because of the Pogles, a television programme and we really did believe that the Pogles lived there. Just lovely things that we did all together and I think we were probably a really happy family. I don't remember any stress or … there must have been money problems but I don't remember feeling that we didn't have money. My mum used to make us dresses, make us clothes. My nana used to knit things; she used to make little cardigans for me with shorter sleeves. I don't ever remember my mum trying to stop me from doing anything I wanted to do. My dad didn't want me to ride a two-wheeler bike because he thought I wouldn't be able to do that but in the end I got another cast off from Susan Carter and he helped me to learn to ride it. There were a few crashes into the rose bush in the garden but he … once I'd made my mind up to do something they were quite … I wanted a pair of roller skates and they said, well, "You can have roller skates but only if you wear a crash helmet" and they got me an old scooter crash helmet and I had to go on these roller skates with this crash helmet on. But far from people laughing at me, all the kids wanted to use my roller skates but they wanted the crash helmet on them as well.

So they made everything possible. They let me take risks, they let me try things. I was in the Scouts … not Scouts. I was in the Brownies, I was in the Guides. I did swimming lessons. I had friends to tea. I don't think I had any different childhood to if I had been born able-bodied. I really do think I just felt like any other child and I don't really remember ever feeling particularly limited by my disability.

I think that's lovely that your parents did that. Outside of your family, did you experience any disability prejudices from other people that you encountered in your life?

I think the only time I really started to be aware of that was once I started trying to find a job.

We'll move onto that in the next part.

At school all my battles were fought by my mum really. She listened to what I had to say which was good, she didn't just take the school's word as that's it, "You can't do that, the school have said you can't do that." She actually … if I said I wanted to do something she would fight to make sure I did the things that I wanted to do and took the options I wanted to take and went on the school trips along with everybody else. There was never any fuss about me not going on school trips. I went to … I went on a German drama tour in a double-decker bus off to Germany. I went to two French exchanges down to the South of France. Both of which we had to get the train all the way down, you know, I don't ever remember being told, "Oh no, you can't go." And I just think, "Wow, how did my mum afford it?" You know, we didn't have a lot of money but my mum just made sure that we had those opportunities. However she did it, I don't know because they were probably quite an expense at the time and I don't think … it wasn't really until I left school that I noticed the money and I noticed that I was different and I was going to start to struggle in life. School life … I pretty much fitted in and felt the same as everybody else.

Thank you very much. That's really really good to hear your answers to those questions. Shall we stop the first part now and take a break and then move onto the early adulthood after that?

Yes, good plan. I haven't got a clue … what is the time?

Okay, so this is the second half of the interview and I'd like to discuss your early adulthood, feelings about your impairment as you approached adulthood and later medical interventions and career, relationships, that kind of thing.

So just at the start of looking at early adulthood, say from the end of secondary school onwards, what were your feelings about your impairment at that period of time?

I think I just thought I was the same … I kidded myself that I was just the same as everybody else because that's how I'd felt as a child. But once you're out into the big wide world, all of a sudden you become a bit more aware of other people's prejudices towards disabled people. Not only in the workplace but out socially, you know, you're much more likely to come across people saying things quite openly in front of you. So I didn't find it particularly distressing or upsetting just a bit of an eye-opener really that it was out there.

And after secondary school did you go onto further education? I know you said you did a typing course.

Yes. I just did a one year secretarial course at school which basically was office practise – shorthand, typing. And then it was out into the big, wide world to try and get a job which I just thought I could do.

When I was at school I had a specialist career's advisor assigned to me and she did set me up on a couple of interviews. But they were really awful experiences where basically, you know, they were the sorts of jobs nobody else wanted to do. So working at the Post Office, for example. And they really were people talking to you in a very condescending way, as if you were about five years old. And one particular interview I was asked, "Can you use a phone?" And I said, "Yes I can." And they said, "Right, is anybody at home?" And I went, "Yes." And they said, "Who?" And I went, "My mum." And they said, "Well, phone her up and tell her that you're staying here for lunch and you won't be back until later." And I said, "I'm not going to do that" and they looked a bit affronted. I said, "My mum's just had a hysterectomy and she's in bed. I'm not going to ring her up." And they went, "Oh well, just pretend." And I did it because I didn't know any better and it's like, "Can you carry a file?" "Yes." "Well, there's a file, can you just carry it over there?" "Here's two files, here's three files." In the end I couldn't see where I was going and it was just sort of putting me through the motions to make sure I could cope with what the job was. And because I'd just left school and I didn't know what to expect from an interview, I just went along with all of that.

And other interviews where I was asked … "Part of this job's going to be making and carrying a tray of coffee and we think you wouldn't be able to do that, would you?" Well, I'd never done that. I was still living at home. So there were lots of really awkward situations like that and at the same time as I was going to these interviews I was looking through the paper and thinking, "Oh, I could go and work there. I could work there" and just writing to them and saying, "This is a copy of my CV, have you got any vacancies?" And one of the places I wrote to were the local council who were in the process of moving from some town centre offices to some newly built, huge, spacious offices on the outskirts of town but right near to where I lived. So I got a response from one of those saying, "Yes, we've got a vacancy." I nearly always got a response saying, "Sorry, we've got nothing." And I filled out loads of application forms and I never got interviews and I didn't get many interviews and if I did get an interview, I didn't get the job.

But I got the chance of this job interview, went along and I got the job and it literally was, you know, not long after I left school. I think I left school in the May and in September I started the job and I was really chuffed and I really felt, like, "Wow, I really can do it" only it transpired later that this had been a job vacancy that they'd been trying to fill for ages and they'd advertised it loads of times and lo and behold, you know, little old me came along. But, you know, in hindsight I don't mind that because it got me on the ladder. It got me on the job ladder and it wasn't much of a job but it got me out of the house and going to a place of work every day and meeting work colleagues. The job itself was really boring. It was just typing all day with another woman who was only part time, sat in a little office on my own but, you know, it was a job which I think nowadays even if you're able-bodied it's quite hard to get a job. So I think it was quite an achievement.

Were there any other people with any other kind of disability or impairment that worked at the same place as you in your first job?

No, it was quite a small office. It was part of a big office building but I was really, you now, it's quite separate. I never met anybody else apart from my immediate work colleagues and none of them were disabled.

And how long did you stay at that job for?

Probably about something like ten years but not in that same job. It was working for Berkshire County Council and I did … we started off in the town centre offices which were quite small and then we moved to big, brand new, open plan, state of the art office buildings out of town which was good because then all of a sudden I was integrated with many more people and, yes, I did then start to see other disabled people. I mean obviously disabled like wheelchair users. There weren't many but I did see some.

But I started off working in the Education Department, working on free school meals and free school transport filling out really boring letters to parents or to schools giving out information or asking for information.

From there I went on to work for the social services department and that was a bit more interesting and once we moved to the big, out of town offices, I was sat next to a girl who was a similar age to me and that was good because all of a sudden I had a mate and we used to start going out and going to nightclubs and things.

I then found another job working … that was it, they brought in computers and word processors and they tried to … they had one word processor for the whole department and nobody wanted to use it. So I decided I'd use it seeing as it wasn't being used by anybody because it was much easier for me than working on a golf ball typewriter, threading pieces of paper in and out. Here was a great big machine, you just pressed a button and out flew a bit of paper.

And then I saw another job that was advertised in the council for a word processor operator which was much better pay but actually was a much worse job, I discovered, once I'd got the job. Basically you were just sat plugged into an audio machine all day in the legal department typing great bit lengthy conveyances and things and there was just no fun at all in that job. You weren't allowed to talk. There was just an in tray, an in cupboard with great big thick legal files with a little audiotape on top. So it was enough to make anybody feel depressed. Whilst I was there I tried to encourage them to make the job a bit more varied. I said, "We don't mind doing the photocopying. It's good to give us a break from the earphones."

So after I'd stirred up a bit of fuss there then I actually left and went to work for Blue Circle Cement which, again, was … that was a bit of an eye-opener for me because it wasn't protected like working for the council was. It was a private industry and I was quite shocked to have been given the job because I really did feel it was out of my league. And it was quite a long commute each day out to Aldermaston which is probably about twelve miles away from Reading along quite … well the back route was along country roads and I found myself going to work in the dark and coming home in the dark in the winter. It was all right when we were there but, again, it was a private company and they expected a lot more of its employees.

Not long after I'd started there they made people redundant because they weren't doing what they were supposed to be doing for whatever reason. And that was just a bit of a shock to me to see how people were treated because private companies didn't treat people very nicely and there were people there that would one day be at their desk and the next day their desk would be empty and they would be gone, and realising that just didn't happen at the council. They didn't make people redundant. They gave people other jobs, they moved them, but they never ever got rid of them like that overnight. And I wasn't enjoying it. I was going … after work I would go to a pub and drink with a friend, not … I wasn't an alcoholic or anything but basically I wasn't enjoying going to work the next day or anything. I was going to the pub so I didn't have to think about work and I would quite often get quite drunk but not to the point of not being able to walk or anything. And thinking that I was having a great time but actually, with hindsight it wasn't. I thought it was great at the time but it wasn't, that was what I did. It was work … I wasn't going every night or anything but it was meeting people, chatting to people, drinking lots of drink, acting silly and going to work the next day.

What age would you have been at that time when I was working for Blue Circle Cement?

I was probably about … when was Princess Diana's wedding? Was it 1987? Something like that. It was about 1987 so I was … '62, '72, '82 …

About 1984, wasn't it, the wedding?

I was about twenty five. I was about twenty three, twenty five, something like that. But …

And were you still … in terms of gaining independence, were you still living at home at that time?

Right. I was looking at that question. I was thinking that's quite an interesting one because I didn't actually leave home. My mum left home. Just because the house I lived in as a child from the age of seven was bought with my compensation money and my parents … they didn't … I don't think they bought the house as an investment particularly. They bought the house because it moved us from the area that we lived in which was sort of quite a rough council area into a much nicer area with nicer schools and I think they convinced themselves that the move would be good for me, but it would be good for the family as a whole. And my dad being the sort of person that he did, that wanted everything for doing nothing, I think just saw it as a nice easy way to get a house. My mum was a bit more practical and said, "Right okay …" they didn't just buy a house, they bought this house that had been empty for ten years and needed lots of work doing to it but my dad was, like, "I can do all of that."

So we basically moved into this shell of a house and my dad had to re-wire it, re-plumb it. So we were living in a building site for quite a few years whilst he did all of that and it was a lovely house and it was my childhood home, probably the place where we spent the most amount of years. But it was a big old house with a lovely big garden; big rooms and I don't think they shouldn't have done that with my money. I think it was a shrewd move and what they didn't realise was that it was a really good investment because house prices just shot right up. I think the house was bought in about 1972 or something for about ten and a half thousand.

Wow …

And about seven or eight years later it was sold for about sixty two thousand. So it had made six times what we paid for it but, at the same time, it had been uninhabitable when we moved into it and my dad had done all this work to make it habitable. So we lived in that house all together as a family.

Then my mum and dad started arguing and separated and at the same time …

How old were you then, when that happened?

I would have been about eighteen / nineteen. So I'd just started work. And I think my mum decided we should move to a smaller house, one that would be easier to maintain and run. It had a massive garden, the house we had, we had vegetables and everything. I'm pretty sure that would have been her decision. So we moved to a smaller house but this is where I kind of found it quite difficult because I was aware that this house was being bought with my money. So I kind of bagsied the biggest room for myself and I think I was quite obnoxious and horrible about it, but that was my age, saying, "Well, I'm going to have this room" and none of the rooms were that tiny but my mum had a smaller room and didn't create much of a fuss about it. And I can remember at that time being quite frustrated because I'd have loved to have just moved out and had my own place but I couldn't because this was my house and I'd make my family homeless.

So I kind of tried to make my own place by setting my bedroom up like a bedsit. I had a drinks' cabinet that I bought from MFI and put together and filled it up with all sorts of horrible things like Dubonnet and bottles of Ouzo that I'd got from my Greek holiday and bottles of lemonade and cider and I thought I was being really grown up. But my sisters would come in and drink it all and I couldn't have that so I put a Yale lock on my bedroom door and my mum was absolutely horrified that I could lock my bedroom door and I had a key to let myself in and out of my bedroom door. So my mum had quite a violent temper anyway and I remember one particular time her taking a hammer and basically hammering a hole in the door to try and make me open it. And I was terrified, I thought, "I'm not going to open it, she's going to kill me." So I just cowered in my bedroom and I could hear this hammer being smashed at the door and I remember thinking, "Oh my God!" But, you know, I realised, again, it was just me being a teenager and it must have been quite frustrating for her that she couldn't just come in and talk to me.

But also you were in a different situation to most teenagers in that there was a strong amount of the financial side of your lives that was your finances, wasn't it? So in a way you were kind of being given this gift of all this money without being mature enough to know what to do with it.

Well, I never saw it as money but I definitely saw it as a house and, you know, "Wow, I'd quite like to have my own place but I can't do that because if I sold this house my family would be homeless." And my mum had been saying to my dad, "Look, we're really lucky to have this opportunity but what we should be doing is saving some money because one day she won't want us to be in her house and we'll have to have our own house and we'll have to start saving together a deposit for a mortgage" and my dad was just, like, "Oh well, whatever, we'll do it at some point." He never really planned for the future.

And my mum obviously was a bit more sensible than that. I mean my poor mum was trying to keep up this massive house and work full time and go through a divorce and, you know, trying to maintain this house and my dad wasn't really contributing financially. He had a bit of a rubbish job as a service engineer. He didn't earn a lot of money. But I think more likely, as well, was that he was just gambling a lot of it away in fruit machines. He'd go to the hospital to meet my mum from work and probably get there about an hour before she finished work, be drinking pints of beer and pouring money into a fruit machine. And, you know, I don't think any of us will really know the extent of that. But he used to play Spot the Ball and all these little things all add up. And he did start drinking more. And it was only, like, bottles of cider but, again, we didn't know how much he was drinking because he would sort of drink in the sitting room with a bottle by the side of him and a glass by the side of him so it wasn't as if you saw him getting up and opening cans. It was just glug, glug, glug and he'd be sitting there drinking some cider. And I never saw him drunk, I never saw him falling over drunk but presumably he needed that alcohol.

So my poor mum was trying to sustain the whole family on her salary as well as work full time and, like I said, we never missed out, I don't think, on trips or having clothes or being able to do things or having holidays. We never went on expensive holidays, they were always dead cheap holidays but my mum always … I never remember anything about "We haven't got enough money to afford this or that or the other."

When I was about … so I was about seventeen / eighteen / nineteen, my sisters both had left school and went off their separate ways to college – one up to Loughborough and one up to … I think one of my sisters had a gap year and then she worked locally. But then she also was having huge arguments with my mum because she was a teenager and ended up going to live with my dad, which I'm sure she didn't like but she enjoyed the fact that she had more freedom and she and my mum were always clashing and arguing and at each other's throats. So one way and another there was always … at the same time, my sister went off to college, my other sister was living with my dad and my mum met and married someone else and went off to live with him on the outskirts of Reading. So, you know, I joke about it and say my mum left home. She went to live with this new step dad.

But that worked quite nicely because then I had my own place which was what I really wanted and it was quite exciting. I was suddenly on my own and in charge of this great big house. It was a four-bedroomed house. And having to buy pots and pans and, you know, dustbins and I sort of went a bit mad and got some new bedroom furniture and … but it was a bit lonely so I had … not because I needed it financially but I had lodgers who were university students and a friend of one of my mum's who decided she didn't like living at home with her mum so she came to lodge with me which was quite funny really because she was only, like, a five minute walk from her mum's. And I think she was just going through the motions really. She was living away from home but she didn't enjoy it. She didn't like cooking, she didn't know how to cook, she didn't know how to look after herself really.

So did you have … at that point did you have access to your trust funds yourself? Were they still mostly being controlled by your parents?

No, my parents wouldn't have had any control over it. I think what I did at that age was I … my money had been just stuck in the bank and I actually took it out and did some different things with it like took out some ISAs and TESSAs and things like that. I didn't just spend it because I was working and I had money from my work. And I can remember suddenly being made aware, as well, that there was money in the Trust, the Thalidomide Trust, so that was separate. It wasn't my private trust money. But writing to the Thalidomide Trust, the one memory I have is asking for money to buy myself a new pair of jeans and thinking, "Ooh, this is really nice. I can just write to them and, you know, I get this cheque back and I can go and buy this new pair of jeans." It was only a pair of jeans but it seemed like huge megabucks to me. I think this must have been before I worked and going and buying this new pair of jeans seemed to cost an absolute fortune.

So suddenly being aware there was this money that I could actually write off to them and get, you know, I had to get used to that slowly. It wasn't like my family had ever used the money or abused the money. It had always been left.

There was another incident where … because I think both my mum and my dad, when the private trust settlement was sorted out, got a little lump sum each, and my mum had used hers … I don't know what she'd used hers for actually. But my dad had … I didn't know at the time but it came out later on. When he separated from my mum we were at the pub one day and we talked and he said, "Oh, you might remember that, you know, when the private trust was sorted out, your mum and me both got an amount each" and I don't know what she'd … I can't remember what he said she'd done with hers. But he'd basically used his towards doing up the house. So I was wondering what on earth he was telling me this for but it basically got around to him more or less saying, "So you owe me this amount of money." So I think he must have hit desperate times because all of a sudden he didn't have my mum to support him and he was having to live … there was no buffer. But I just kind of remember looking at him and I must have had a bit of a look of horror and disgust on my face but not reacting in any way, not angry. I didn't say anything angry. I didn't say, "When do you want it?" or anything. I didn't really acknowledge what he'd said. And he didn't say it in so many words, it was like one big hint which I just ignored. And he never said anything again about it. I never told my mum about it, she would have just been horrified. But I can remember thinking how dare he? How dare he?

And when I think about it now I think, well, he lived in that house all those years, rent-free, and a lot of the things that ended up later on being done to the house like we had a big downstairs extension on the kitchen and a downstairs shower room, he basically got paid for with my trust fund but said it was me that needed it. And it was good having a downstairs shower room and the same thing … we had a car that was old and conked out and he said to the Thalidomide Trust that he needed money to have a new car to drive me around and it's not really until sort of later that my mum told me those things that I realised things were going on. So I think it's thank goodness that my mum wasn't the sort of person too that my money wasn't embezzled on this, that and the other. Because my dad probably would have had some ideas on how to make a fortune and asked for some money to invest in it and lost me a whole lot of money because, like I said, the house idea actually did me a favour. Although I don't think it was ever purchased with that in mind.

That's interesting, isn't it? Because it adds a different dimension to family life when you have issues to do with a trust fund being set up for one member of the family. So it's very interesting to hear you talk about that actually. And so the moment you mentioned this time when you realised that you could ask for some money for some jeans, what sort of age would you have been then, do you think, around then?

For the jeans I was probably around fifteen.

Okay. So you knew by fifteen that you had money in the Trust.

Well, we started to go on the Thalidomide Trust holidays and they were organised holidays … basically took a group of probably about thirty or forty of us off to a different destination every year. And you could choose where you wanted to go. We got a list of, "These are where we're going to go" each year and which one do you want to go on, your first or second choice.

Was that the Thalidomide Society or the Trust?

No, it was the Trust.

The Trust, okay.

And, again, I don't know why they did that. But it was brilliant because basically it meant that we could get away from our families and it was basically like an eighteen to thirties holiday in that you were just taken away to somewhere really hot and nice. You had a certain amount of spending money, it wasn't a huge amount, but, you know, spending money. But you went on a plane and for most people at that time a plane journey was unthinkable. And my first holiday was to Corfu and I didn't even know where Corfu was and neither did anyone else. So they'd ask me and I'd go, "I don't know." But to suddenly be with a great big group of people just drinking and smoking and just doing what you wanted … and there were helpers but they were only there to help us, they weren't there to tell us what to do and what not to do.

So were there parents there as well or was it just thalidomiders?

Just thalidomiders and a group of helpers.

And was this the first sort of contact you think you might have had with a big group of thalidomiders all in one place at once?

Yes. Yes. So I think those of us that went on those holidays were closer because our history goes back further and we know more people as a result of that and we've got more things to talk about. "Oh, do you remember the holiday to so and so?" And, at the same time as well, I don't know whether anyone's talked to you about the holiday place in Jersey that the Thalidomide Trust bought? But there was that as well which I didn't start going to until I was a bit older. Probably my first holiday there was when I was about seventeen or eighteen. But, again, here was a place that you could go and you were safe but you were away from the family and away from home.

And the Trust holidays abroad were fantastic but I can remember feeling very sad when I came home because all of a sudden you were just on your own again after having been surrounded by all these people that were just all intent on having fun and going to places like Disney World and New York and Orlando and the Everglades and New York and Miami and … they were just places that nobody else … well, more amazing is the fact that they were taking a group of quite severely disabled children to these places. I mean they wouldn't have … they probably would have gone out; knowing the Trust, and had a look at the places they were taking us to. But it was in the days before they would have had wheelchair accessible vehicles. So they were lifting people out of wheelchairs and up the steps of coaches and having to lift people out of showers … they weren't adapted hotels, they were just hotels that we had to manage in and how none of us got killed I don't know. I mean certainly there were a few injuries. There was one injury where a girl was being carried by somebody. She had no legs and she was waiting to use a toilet and while they were waiting the helper propped her on the edge of a sink and because it was a

Greek sink it just collapsed. Just smashed. And the girl just crashed onto the floor onto the base of her spine and it was things like that you just think, “Oh my goodness.”

It wouldn’t happen now, would it?

No, it wouldn’t happen now. I’m really glad it happened then. Not that she got injured, I’m just glad that the holidays happened.

So would … tell me what age would you have been when you started going on those holidays and how many years would you have gone on them?

It was literally once I’d finished school so it was probably when I was about fifteen or sixteen and we must have gone on them for about ten years … not that long. Eight years / ten years or something. And there was a little lull for some reason and then they did do one more holiday which was to America and it was a three centre holiday so it was Los Angeles, Hawaii and San Francisco and that holiday was a bit different because all of a sudden, I suppose, we were all getting a bit more grown up and a bit more sensible. And I just remember it not being … more like there were little cliques developing and people being left out and some people being a bit nasty. So I can remember really thinking it was going to be just the same and it wasn’t and I was a bit disappointed. And I think that was the last holiday that they did which was just as well because I think they stopped doing them at the right time really.

And apart from those holidays which I must say sounded absolutely fantastic, I would have loved to do that when I was sixteen with a bunch of friends, did you go to the yearly events put on by the Thalidomide Society with your parents or your friends?

I never remember going with my parents to a Thalidomide Society event. I might have done but I really don’t remember it.

Do you think they did? Did they go along to the AGMS or …

I think there used to be meetings in London that they used to go to but if I went with them I don’t remember it. It wasn’t … it didn’t involve me.

And apart from those trips, the Thalidomide Trust holidays, did you have contact with other thalidomiders in general then or were most of your friends non-thalidomiders.

Most of them were non-thalidomiders and probably still are. And I find it quite weird, like this party we went to at the weekend, thinking, “Wow, if I had a party I wouldn’t want this many thalidomide people at it.” But then I think I always had some friends that were thalidomide and friends that I saw from time to time because they didn’t live nearby. I had a holiday romance with a few on different holidays. I kept in touch with them and then it sort of fizzled out. And there was one who I sort of met whilst I was in Jersey and it was sort of a girlfriend / boyfriend but nothing too exciting went on. But I used to go and visit him at his family's house and he used to come and visit me at mine. But he was a wheelchair user so really the amount of help he needed meant that he couldn't come and visit me without some help from his parents so he had a brother who lived nearby. I remember an occasion when he was brought to visit me and sort of like left with me for the day whilst his family went to visit his brother and then they came and picked him up at the end of the day. So it was, you know, didn't see him very often because he didn't live anywhere near me but …

And do you think … would you say that peer support and having contact with other people that were affected by thalidomide was important to you when you were growing up?

I would say not really. I suppose it was … to me it was a big group of people that were the same age as me. It wouldn't have mattered who they were, whether they were disabled or not. But obviously, going on trips where they had things going on for us where we could all join in and be encouraged to do so by others was good. But I wouldn't say really that peer support became valuable until we were all that bit older really and started having children type of age.

Yes, yes. Going back to the issue of you gaining independence, so you were living in your … in what was your family home on your own and did you have to have any support in caring for yourself and looking after the home at that time or were you able to live completely independently?

No, I must have had … I mean I had lodgers and I'm sure they might have done bits for me but I didn't depend on them. And I also had a cleaning lady. But when I think about it I was working full time so I think even without the disability I would have … well definitely because of the disability I had a cleaning lady because I didn't have the time or the energy to do cleaning and working and feeding myself when I came back from work. But, you know, they would have come for about an hour a week, just doing hovering and dusting. I remember my younger sister living with me when she was back from college, doing things like decorating a room and I can remember friends helping me decorate rooms but I didn't … I don't remember ever paying anybody. My mum might have done a bit of wall papering and I can remember doing the garden myself. I never, ever had help to do the garden. It was a tiny little garden, mind you. Or I might have enlisted one of my sisters to come round and do a bit of weeding or my mum might have done a bit of weeding when she was visiting me. There wasn't really any formal care at all.

Interesting. But you continued to get some family support and were you still in touch with both your mother and your father at that time?

Yes. They both lived locally and they'd both come and visit me or I'd go and visit them.

And what about close friendships, what sort of … did you have any particular bonds with people at that time?

Well I had this girl at work who I was friends with all the time I was there so those ten years …

That was at the Blue Circle Cement …

No …

No, that was at the County Council.

Yes. I still, I think, stayed in … no, I didn't really stay in touch with her once I worked at Blue Circle. I think when I left we just didn't see each other so much then. I think she might have had a boyfriend by then anyway. But I used to go out with my lodger, who was one of my sisters friends, she was one of my people that I used to go drinking down the pub with. But I still used to see my friend Donna who was my friend from work. But obviously not as much. And at the pub I made new friends who we used to hang around with and sort of go to parties with and so on and so forth. I think it was just … with Donna I went on a couple of holidays with her and I can remember thinking I was perfectly normal then, as in the way I looked, and dressing the same as she dressed and convincing everybody I was just normal but really I wasn't, you know. I was wearing the same awful court shoes that she was and probably really struggling to get about but I just thought because I was doing it I was convincing everybody that I was just the same as her which is quite funny looking back now because it's a bit of an age thing because you're a bit of a sheep at that age. You just follow your peers and do whatever everyone's doing and when you get a bit older you think, "Oh, sod that. Flat shoes are a lot more comfortable and I'm not going to do that any more."

What about things like clothes, did you have to adapt clothing?

If I bought trousers, they had to be shortened. If I bought anything with long sleeves the sleeves had to be shortened. If I bought skirts they had to be taken up and I really hated sewing but I had to be good at it really. I had to be able to use a sewing machine. I had to know how to sew and that had to be part of my life and people used to say to me, "Isn't it good that you can sew?" But because I had to do it, I didn't enjoy it; it was just something I had to do.

So you always did it yourself? You didn't get help?

I think my mum did it when I was younger and then I bought myself a sewing machine and started to sew my own things. If I got a really nice outfit … I remember once paying a dry cleaner to take a skirt up for me. I remember once paying to have leather jacket … to have the sleeves taken up on that because it wouldn't be something I could have tackled. But other than that I sort of think I did everything myself. But obviously where possible, I'd try to choose things that didn't need to be adapted or altered. I remember one particular day going with my friend at lunchtime from work to buy a pair of jeans, yellow jeans, that I decided I was going to wear to the nightclub that night, and I bought some cotton and a needle and I went into the toilets at work and sewed one leg whilst she sort of covered for me if anybody asked for me. And then I changed the guard and she went to the toilet and sewed the other leg for me so I could wear these jeans that night.

And how about things like health concerns and medical interventions at that time. Were you still having to have any regular check ups at the hospital or any further surgery or anything like that?

No. I carried on going to the hospital for, like, an annual check up with this consultant. Probably until I was about thirteen and my mum used to have to take a day off work and take me along and there would always be a long wait and I just … my memories are just having to strip down to my knickers and vest or knickers and bra, walk up and down, and I can remember him having really bad breath and being really old in my eyes. And all his students standing there while he told them about the operations he'd done on me and about my history and he'd say, "Walk up, walk down. Walk back again. Right." And I can just remember not really understanding why I did it but doing it anyway and eventually my mum just said, "Right, you know, what is the point of her coming to these? Does she really need to come any more?" I think she realised there was no benefit to me or to her and we just decided I wouldn't go any more and the problems I was having … I just had a bit of arthritis in one hip that I'd got some painkillers for from my doctor.

Other than that I was really healthy. Never been near a … might have fallen over and needed stitches a few times. I've been doing that throughout my life; still do from time to time. But, you know, it's just falling and not being able to stop yourself from hitting your head on something … it cuts it open really.

And apart from … you mentioned getting your first job that you were aware of certain prejudices against your disability at that point, in other aspects of your daily life were you aware of any other disability prejudices?

Not really. I mean the only thing I can remember is when I was advertising for a cleaner in the local post office and a phone call came through and it was an elderly lady who said, "Oh, you're advertising for a cleaner?" And I said, "Yes." And I was trying to explain to her where I lived. I said, "I live in one of the four Georgian styles in such and such a road, do you know where I mean?" And she said, "Oh, yes, I know the houses. I think there's a crippled girl who lives in one of those." And I said, "I think that might be me you're talking about." And she said, "Oh, oh …" I said, "I've got short arms." And she said, "Me and my husband, we always say how well you're coping when we go past and you're cleaning your car," back-peddling like mad. And people always say, "You didn't give her the job, did you?" I said, "Well I did actually." But, you know, she was fine. And she just accidentally walked into a bit of a trap that I hadn't intended to set for her. But that was just her age really, inappropriate use of language and, you know, again, when I was going to pubs or what have you you might hear someone going, "Oy, oy, that's your one over there. But I just think, well, that's the sort of thing that I did if I saw a really fat chap or something. It's the sort of comment I'd make to one of my friends. I don't think I ever remember anyone being very rude directly to my face or stopping me from doing something because of my disability.

Talking about … moving on to talk about relationships. Did your impairment in any way … or did you perceive your impairment as affecting your ability to find a partner?

Well, I think both my sisters, from quite an early age, had boyfriends. From school sort of time. And, you know, both sort of had boyfriends throughout their lives really. And I don't remember it bothering me particularly but I can remember my mum saying something along the lines of, "You shouldn't let it bother you, you know how upset they get by their boyfriends and don't worry about it. One will come along one day for you and when he does, he'll be the one" sort of thing. I don't ever remember feeling left out, fed up or depressed.

But I always had lots of friends and I always chatted to blokes. In the pub I can remember I never, ever had a problem chatting to someone, starting up a conversation and that's perhaps what made me popular. I look back and think, well actually that's why all my mates liked going out with me because I'd start chatting to blokes and then they could just muscle in and end up with them. But I didn't mind that, you know. I didn't mind it and even now I just think I met a lot of nice people who liked talking to me and what's wrong with that? It's quite nice.

The 1980s was all about image and so at the time I didn't realise it because, like I said, I was convinced in my head that because I wore the same clothes as everybody else that I was normal. But, you know, in reality at that time image was everything and it wouldn't have been … if people were seen with a disabled partner it would be seen as the fact they couldn't do any better. And I think that is absolutely true, without a doubt, and it's no indictment upon me as a person, it's just how it was. People just saw it as not being able to do better for themselves and they would have got teased for it. They would have … they just wouldn't have even talked to me in case someone said, "Oh my God, I can't believe you're talking to her. What you talking to her for?" And it never struck me at the time; it never bothered me at the time. But I can look back and say, "No, absolutely it was all about image."

And at that age you're just consumed with looks and how people look and whether that chap looks nice and that one's got sticking out teeth, don't want him. You didn't care about people's personalities and anything really. It was all about how people looked.

And when did you have your first romantic relationship with somebody?

Well I had little holiday romances on my Thalidomide Trust holidays. So my first ever kiss was with a thalidomide boy in Portugal called Willy Critchlow. And he was a Geordie, couldn't understand much of what he said but he was very sweet and nice and I still see him, I've still seen him more recently. And, again, it was just kind of what you did. And I can remember coming home and writing long letters to him and him writing me long letters back. And then he came to visit me when I lived on my own and I remember thinking, "Oh my God!" Because it suddenly didn't feel right, it wasn't a holiday romance, he was coming to visit me. And I can remember insisting to my friend that she didn't leave us on our own because I didn't fancy him any more because it wasn't a holiday, it was just reality. There was this chap arriving on my doorstep and I didn't know what to do with him. So there were a few sorts of romances when I was on Trust holidays.

I had another one where … my first sort of non-thalidomide person, I suppose, was … a friend of mine had been going to a pub locally and she said, "Simone, you'll have to come to the pub, there's this little bloke, he'd be perfect for you. He's really short. He's really nice." And I went down to the pub and he was almost like a midget, he was very short, but he wasn't a midget and thinking, "Oh yes, he is rather nice." And I can't remember how on earth it happened but I did end up going out with him. But it wasn't ever discussed like, "Are we an item?" It certainly didn't last very long. And it was almost like he didn't actually want to be seen anywhere with me. So he used to go and drink at this pub regularly but he never took me there and he went with me once to visit some friends of mine that live in the Cotswolds and I can remember him going there with me to a party or something. But really nothing ever happened; it was just a bit of kissing. He might have stayed the night but we just slept in the same bed. Nothing sexual happened. And then one day he just didn't bother to contact me again. I mean he was quite a nice chap. He took my car off and got it serviced. He worked in a garage and he seemed to sort of want to … I can remember him buying me a Christmas present but obviously he didn't want anything serious and he didn't want to hurt my feelings or tell me to get lost. So in the end he just sort of ignored me which was obviously at that kind of age. I guess I was about eighteen or nineteen and I was completely devastated. He just hadn't bothered to say, "We're not going out. I'm not seeing you any more." He just sort of disappeared off the face of the earth. So I kind of felt a bit heart-broken at that time.

And then I met my ex-husband in 1989, so I was twenty seven. And he actually … I met him at a Thalidomide Society event which was up in Runcorn and I'd actually seen him before. He had a friend who was thalidomide and this friend's mum had been part of the organising committee and she'd got him and his friend to do the disco. He was a deejay. And he wasn't thalidomide. And I can remember thinking, "Right, this year it's either going to be really good or everyone's going to get drunk and it's going to be really boring." And I can remember looking round and seeing all these people with drinks lined up thinking, "Oh my God, it's going to be really boring."

So when you go to a disco you never really look at the deejay as potential but he'd actually been … he was stood by one of the doors whilst his mate was running the disco, with a pint. And I just stopped and started talking to him and it kind of went from there really. We ended up going outside and chatting and having a bit of a kiss and I'll never know really to this day whether it was set up. But basically his mate left him, packed up all the gear and left him at this hotel with me. So, again, he stayed in my room but nothing happened, there was no sexual activity. And the next day I gave him a lift back to where he lived in Liverpool. I didn't go to his house, I dropped him off at the station I seem to remember, and said goodbye. And off I went back to Reading. And on the way back I stopped at some friends and said, "Oh my God, I met this really lovely bloke. Oh, he's lovely. And it's like this, it's like that." And he wasn't really committed about whether he'd see me again or ring me. I think we did swap phone numbers.

Anyway, I think there was a bank holiday coming up and I said, "Oh, you should come and visit me in Reading." And he said, "Oh, I'd like to but I've arranged for some people to come around for a meal at my house." So I went, "Oh, all right then." But then he phoned me and said, "My friends aren't coming now so I could come and visit you." So he came down to Reading and visited me and it kind of went from there. For a long while it was kind of a long distance relationship with him coming down weekends and visiting me. And I don't really remember how far into it something sexual happened but it did and I was a virgin up until that point and I told him that but he didn't believe me really I don't think. And I can remember him … because he was his own boss, he worked as a gardener, so he could have odd days off so he could have a long weekend down here. But he never wanted me to go and visit him. "I'll come and visit you if you want." And he'd say, "Well, I've got a lot of work to do to my flat but when I've done that you can come up and visit me."

So I started to think, "Well, maybe there's something he doesn't want me to see up there." I used to phone him up all the time and he used to phone me and we used to visit each other. So one day I'd had the day off from work on the Friday and I just thought, "I'm just going to go up there and surprise him, bit of a risk." I was lying on a sun bed at the time I remember. So I'd had this sun bed, I'd had a haircut, got in my car full of weekend stuff and I drove up to where he lived. And I said I was going to phone him up that night. So I phoned him up but I was sat … it was in a phone box. It was before mobile phones. I phoned him up and said, "Hello. Guess where I am?" He said, "I don't know. Are you at your mum's house?" And I said, "No, no." I said, "Such and such a road, does that ring any bells?" I didn't know exactly where … I couldn't find his road but I knew I was in the vicinity. He said, "Oh, you're joking." I said, "No, I'm here. I've come up to see you." He said, "You're joking." I said, "I can't find your road." He said, "Well …" I think there was a station or something. And he said, "Get to that station and I'll come and meet you." So drove to the station and he got in the car and he kept looking at me and I could see in his face it was like disbelief that I'd just turned up on his doorstep. But he wasn't angry, he was quite relieved really.

So we went back to his flat and it wasn't really … it wasn't a tip or anything. I think he just wanted to impress me with something more than it was and then without about half an hour of me arriving his twin sister turned up … I think he'd phoned her up to say, "You'll never guess what, Simone's come up to visit me." So she was around like a shot to … now I know her that was very typically her, turned up to see who this girl was who her brother had met. And I think that weekend I went round to meet his mum and they were very nice and polite and welcoming and went back home again. And so that carried on for about a year and after a year I said, “Well, where’s this going then? What’s going to happen now because we can’t carry on like this forever? It’s a bit of a palaver commuting backwards and forth down the country.” And we decided that we would get engaged and that he would move in with me and that we would get married about a year later. So it was all sort of planned. I was never asked whether I wanted to marry him. It was all just a … probably me arranging it all. I don’t remember, but probably.

And did your impairment in any way ever affect your relationship with him? Did he ever speak about how he felt about it, or his family’s feelings about it?

I don’t think so, no. Because they met me straight away and knowing him as I know him now he probably wouldn’t have said much at all. He probably would have told them I was disabled but they knew his friend so they kind of knew his friend and they probably would have based their idea of me on him and he would have been quite outgoing and forthright. So no. I don’t ever … I just remember feeling welcomed and quite normal to them.

That’s very good. Do you want to take a break for a second and have a quick drink?

Yes.

So did you and your … first of all tell me about your marriage, when you got married.

Well, I think I just wanted a sort of traditional wedding. I think most women do, don’t they? In a church, bridesmaids, white dresses.

How long had you been together before you got married?

Two years but we got engaged after about a year and we planned exactly when we were going to get married. So, you know, from about a year into it, we knew when we were getting married. And I was very excited about it and went to wedding fairs and I had all kinds of ideas about the dresses and the flowers and the cake and, you know, did everything that brides to be do really. I decided I was going to get my dress made because it would be easier than trying to get something off the peg. And my sisters would be my bridesmaids and they would get their dresses made. And then I had … John’s two little nieces were going to be bridesmaids and one of my good friend’s son and daughter … I’d always joked with her when we were younger that they’d be in demand for page boy and bridesmaid, they were really cute little children. So they were booked and they were all kitted out in Laura Ashley, like, sailor outfits, dark blue sailor outfits and my sisters had dark blue dresses and I had an ivory raw silk dress that was made for me in a shop in the Cotswolds. And that was quite nice because we had sort of days out with my mum and both my sisters to go for different fittings in the Cotswolds.

Sort of basically went to a wedding fair, saw somebody we wanted to do the cake there, saw somebody else we wanted to do the flowers, somebody else we wanted to do the photography. Went up to London, chose the engagement ring, chose the … it came, I think we went back and got the wedding rings separately at a later date to match the engagement rings we'd got. Got married just round the corner here in a big church and when I was little that was like … that's where I want to get married when I'm older which was quite handy because I was actually living in the area. I was living in this house by then. So I was living in the right area for that church. Started going along and seeing the Vicar and having the bans read. And that's me in my element really, organising something like that. So we got married on June 1st, 1991, sort of quite a traditional wedding, really, everything that you expect it to be.

And were you still … where were you working then? Was that ... you'd have finished working at the Blue …

I'd gone back to the council. Oh no, I'd …

Blue Circle Cement, you weren't there any more?

No, I'd actually … from Blue Circle Cement I went back to the council … no, I went to work for a charity for a year unpaid and that was great fun but it didn't pay me any money. Again, it gave me lots of good opportunities. It had a horrible title: Bulmershe Resource Centre for the Handicapped and it wasn't as a result of being handicapped that I got the job. It was a small charity doing lots of quite interesting work like they set up a couple of group homes for children with severe learning and physical disabilities. But instead of being like an institution it was like the small group homes that are likely to exist today where they were given the best of everything. They were given their own rooms, they were given the best of everything because it wasn't hard cover floor everywhere, there were carpets. They were given nice food, they were taken out on regular shopping trips with the staff. So for the time it was quite innovative work they were doing.

And we also set up something that was a bit like early email. It was call Deaf Fax and it was basically for deaf people to be able to communicate with each other.

Interesting.

Basically any little person who popped their nose through the door of this place, the Director would find a job for them. And if there wasn't a job he'd make one up and get some funding and give them a job. So there was another girl who'd come for an interview for some … teaching dancing to people with mental health issues. She didn't get the job so … but what she was training to do at college was graphic design so she set up a little graphic design studio in the charity and was, like, offering cheap graphic design services to people and running it as a proper business. And while I was there I was doing a bit of this, a bit of that and a bit of the other really. Anything that he could find for me to do.

And is that where you were working at the point you got married?

Yes.

Sounds fantastic.

But I'd just moved. I'd literally just moved because I can remember moving back to the council thinking … because he kept saying, "We'll find some money to pay you, we'll find some money to pay you" and the actual working conditions weren't great. It was a little portacabin building, really, really hot in the winter. Really hot in the summer, really cold in the winter. You had to go outside to another building to use the toilet. Some of the people who were there were a bit weird, like literally you never knew who the Director was going to find next. So one of the people we had on work experience, for example, he said, "I've got somebody coming here tomorrow on work experience, Brenda, I'd like you all to welcome her." "Yes, of course." Anyway the next day this person comes through the door and it's quite obvious it's a transvestite dressed up as a woman. And the girl that worked round the graphic design studio, she's just one of these people that would be very loud, very outspoken and very outrageous and it was like, "Oh my God, Debbie don't say anything. Don't say anything." He'd say, "Hello, I want you to meet Brenda. Brenda's going to be working." "Hello everybody," you know, like a man's voice. It was a not very convincing woman. Very thick make up, hair all shaved off the arms, a grey wig that looked like the post mistress on Postman Pat, you know. Grey with the little curls at the end. So anyway Brenda says, "Can anybody tell me where the toilet is?" So Debbie goes, "I'll take you." And they've both left for the toilet and everybody goes, "Oh my God, why was Debbie so eager to take her to the toilet. So the next minute we see Debbie running back across the car park. She said, "I only took her because I wanted to see if she went in the men's or the women's." We said, "And?" "She went in the women's." "And?" She said, "Well, I looked underneath to see which way her feet were facing and they were facing the right way but she said the trickle was decidedly suspicious.

And it was really weird because after a while you actually forgot that this was a man and you were convinced by the fact it was a woman yourself and you forgot about it. You forgot that she looked a bit different so when people came to the building you sort of saw their faces and you'd kind of think, "Oh yes, of course …" and if ever you talked about periods or anything the weird things was that this Brenda was knowledgeable to the point of not being actually convincing. She knew too much about the subject, more than the women.

And she never actually admitted to being a man?

No, no. Never entered the conversation because, you know, we didn't ever say it, we just ignored it really. We pretended that we were completely taken in.

That's fantastic really, isn't it?

But the nice thing was for her / him, they would have felt truly included and accepted. So I worked there for a year, went back to the council because there was a promise of them getting me some pay which never materialised. I got my job there quite quickly and easily so I was working there when I got married, working as a secretary for one of the Assistant Treasurers or something. And I've found really I don't keep in touch with people from places where I've worked. I've kept in touch with Donna, who's the person that I made friends with and I still do see her from time to time but there's very few people locally. I tend to just like take up with the new people.

And what was your husband's career when you first got married?

He was a gardener still. He worked for himself up North. He couldn't drive, hadn't ever learned, moved down here and to start off with he got a job working for somebody else on a great, big privately owned garden which paid nothing but he could get there on a bike and it was a job. And it's quite funny because I think at the time then I was getting lots of strange … well, lots of strange comments about how he was in that job about how he was angry and he didn't care about tools, he didn't clean them properly and I'd think, "Oh right." I mean I didn't get to hear about any of this, only after he left from his work colleague who was a handyman, I think, working at the same place.

I said to him … then he decided he would set up his own business but he was working at this place while he did that. So we leafleted the whole area and we started to get some phone calls and to start off with if there was anything further afield or if he needed a lawn mower, I'd give him lifts. It was in my lunch break or my coffee break or … I don't know how I managed to do it. But he somehow managed to fit his work so that I could give him lifts to places in my lunch break. But it was quite hard work for me and I said, "You're going to have to learn to drive." So I basically forced him to get driving lessons, forced him to take a test and then he got a car and could do his own thing and that was great and, you know, he … it still is quite a successful business. He's not a millionaire but he earns enough to live off and there's a lot of competition in that area so it's something to be quite proud of.

Did you have any children?

Yes, we had one child, Lois, and she arrived in 1996 so we'd been married for five years and I'd never planned to have children necessarily. There weren't any other children in the family. There weren't any children of relatives; there weren't any nephews or nieces. Children were something totally alien to me. The only thing I knew about children was that they pointed and stared and asked awkward questions. And I never thought about having children but I didn't think about not having them and I didn't … I think when you meet someone people say, "Ooh, when are you two getting married or engaged?" And then when you get engaged, "When are you going to get married?" And then it's like, "Oh, when are you going to have children?" And we had two dogs and we weren't … basically I decided to come off the pill and see what happened and nothing really did happen. I don't think I was even really having periods to start off with. I wasn't when I was on the pill and after a couple of years I said, "Well, I need to get this sorted out. I'm not having my periods regularly." And I realise now I didn't know anything about getting pregnant. I didn't realise there are only certain days of the month when you're fertile.

So I went to the doctor and he said, "Probably the best thing to do is to send you to the hospital. They're the best people who if you're not getting pregnant will help you." And I went to the hospital thinking, "I just want to have periods. At normal times." When I got to the hospital the consultant said to me, "Right you're here because you want to have a baby" and it was sort of like a bit of a smack in the face. I thought, "My God!" I said, "Well, I just want to get my periods back to normal." And he said, "With a view to having a baby?" And I'd never really thought about it in those terms and I said, "Well … yes."

So suddenly you're not a woman, you're a machine and their task is to make you have a baby and your task is to do everything they tell you so that you get pregnant which is horrible and it's really mechanical and takes away any spontaneity or anything. Basically, you know, they give you drugs and a chart and tell you how to recognise your temperature and how to recognise ovulation and when your fertile periods are and to make sure you have lots of sex around the time of your fertility.

So was it IVF that you had?

No, it was just Clomid which is a … it stimulates the egg production.

And did you have at all any medical concerns that there would be any genetic element of thalidomide that might pass on to any children that you had?

No, no. Never.

Or that any aspect of your impairment would affect your ability to have children or to look after them?

I didn't about looking after. Strangely enough I just thought about having a baby and thought, "My God, my legs don't really open up that far and how on earth will a baby get out" which is probably what most women think. And I did go and have a scan of my pelvis and as a result of that they said, no woman really knows, until she has a baby, whether or not she can have a normal vaginal delivery or whether she has to have a caesarean. Everything looks hunky dory; your … one side of your pelvis is slightly narrower than it would be on most women but certainly nothing to present a problem or to stop you.

And I didn't … the fertility treatment or monitoring went for about … I think they allowed it to go on for about two years and then they said, "Well, now we need to start doing more investigations" like they had to have a semen sample. They have to scan you mid-cycle … it all starts to get a bit more invasive. And they said that they would do a laparoscopy on me where they basically put a little camera into your stomach and have a look at your uterus and they look for things like endometriosis and they can see your ovaries and all sorts of things. And they did that and they said, "Well, something about your uterus looks not quite right from the outside but because we're only looking at it from the outside, we need to look at it from the inside because it's a bit like a teapot. You can see what shape it is from the outside but when you take the lid off and look on the inside you might find something quite different. So you need to have this thing called a hysteo-salpingpgram" which is where they basically flush a load of x-rayable dye up into your uterus, x-ray it and it will go up into your tubes and show whether or not there are any blockages.

So I went into hospital and had this test which was horrible. You don't have it done under a general anaesthetic and, basically, when they flush the dye up it was just like a really bad period pain. It's only for a short period of time. And as a result of that they discovered that I've only got half a uterus and although I've got two ovaries, only one of them is connected to the uterus because the other fallopian tube is basically just a dead end, it doesn't connect the uterus up. And so they said as a result of that, "We need to be a bit careful now. You definitely will need fertility drugs because your chances of ovulating will be reduced. You're basically just firing on one cylinder.

Was this thalidomide related?

Well, they don't ever know for sure. It does turn up in the normal population. But the chances are it was caused because of that. I had to have my kidneys scanned because they said that potentially if half your uterus is unformed you might only have one kidney so I had them scanned and they are fine. They said if you've only got one kidney you need to carry a Medic Alert bracelet because if something happened to you and the good kidney was damaged and they took it out thinking the other would function, if you haven't got another one you're in serious problems. So luckily enough I have got two kidneys and they both were well formed. They said, "The problem we've got now is we want to give you fertility drugs but we don't want to over-stimulate your ovaries because the chances are you'll have a multiple birth and a multiple birth in half a uterus would be potentially catastrophic.” So, you know, we want to monitor you quite closely. So that means coming in every cycle and having an internal scan of your ovaries to see how many eggs you’ve got. So that was pretty devastating because you basically have this procedure, this big thing shoved up inside you and shone around on your bits and pieces.

So I was coming to terms with that and the fact that now I might not actually have children, that might not be possible. It was starting to look a bit more complicated because I’d grown up believing you just kiss a boy and you get pregnant sort of thing. And I just still to this day say to people, “You think it’s easy getting pregnant but it isn’t. A lot of women don’t get pregnant straight away.”

So I came home with this news and I had these tablets. He said, I’ll give you this one lot of tablets and they’ll make you start with a period and then we’ll start you with the Clomid, which is the fertility drugs. So here’s a prescription for these tablets to make you start your period. Anyway, for some reason I didn’t go and collect these tablets. I was thinking, “Oh God, do I really want to be bothered with all of this?” And knowing if I started taking these tablets it was all going to start, you know. No one likes having periods so knowing that I was going to take a tablet to do that, I didn’t want to do it and, weirdly enough, I got pregnant at that time. I just woke up one morning, felt a bit light-headed. I thought, “Ooh, that felt weird.” Went to the loo and then it happened again and I thought, “Ooh, that felt really weird.” And I thought, “I wonder if I could be pregnant?” And I did a pregnancy test not really expecting to be pregnant, really not expecting to. I’d done lots of pregnancy tests and it was positive and I was, like, “Oh my God!” It was just amazing, you know. I told John and he didn’t believe me at first and then it was, like, really good because I knew I didn’t have to have all these tests.

So that would have been about February and I was given a due date of the November. I told my mum that I was expecting because she didn’t really know about any of the problems I was having with the fertility drugs and tablets and investigations. And I didn’t want to tell her because I didn’t want her to think I couldn’t have children as a result of this drug. I thought, “I can tell her when I’m pregnant but I’m not going to tell her when I’m trying to get pregnant.” And she never asked. She’s never asked any of us girls. That’s not to do with me, it’s to do with my mum, thinking that it’s private; it’s something that you sort out between yourselves. And I told her on Mothering Sunday which was quite a long time after I knew myself. But I told my sister … one of my sisters definitely knew that I was having all of these investigations and was quite excited with me about everything that was going on. And so it was quite an uneventful pregnancy really. Everything was quite normal.

How did people react to you being … you talked to me a little bit off the recorder about people’s attitudes towards disabled parents and disabled people having children …

I never met any negative attitudes from anybody. Most people were quite pleased for me. Nobody asked me how I was going to manage because I think people that knew well knew that I managed everything that I did and also I’m very practical so already I was starting to think about some of the practical issues and how I was going to do this, that and the other. How I was going to change a nappy, how I was going to breastfeed, how I was going to carry a baby around. I was already looking at equipment.

What sort of equipment were you looking at and where would you go to look at that kind of thing?

When I was about six months pregnant I went back to the Mary Marlborough Centre because, interestingly enough, the Thalidomide Society had held a workshop and we’d used their premises. And as part if using their premises we’d had a look around and we’d looked at what they do there and part of it is around adaptive equipment for parents and babies so we had a look at it all and I didn't realise but I was actually pregnant when I was looking at those things so I thought, "Right, well I'm going to go there, for a start, because it's just down the road." Talked to my doctor about it. I mean the midwife was useless, she was an older lady, just about to retire, and she said, "Oh right well, I can tell you all about having a baby and what to expect. But what I can't tell you is about how things are going to be affected with your particular difficulties" or words to that effect. And that made me think, "Better get on with it and sort it myself then."

And my GP was the opposite, he was, like, "I haven't got a clue where to go to to help you but if you can think of anything I can do to make things easier or places you can be helped, just let me know." He was talking about nannies from the nannying college being given job opportunities to come and work with me and things like this. So he was working but he didn't really know what my difficulties would be and he didn't now what to offer. But he did let me be referred to the Mary Marlborough Centre and they had to pay for that so he was supportive. And they were actually really good there because I kind of knew in my head what was going to be difficult. Things like fastenings on baby clothes and breastfeeding and carrying a baby around. And I saw lots of things there. I saw a little lap … sort of baby beanbag feeding cushion, which wouldn't have been any good for me but sparked a little thing in my head, "Oh, I could make a bigger one of those and I can do it sat on the floor." Things like a sling. "Yes I can use a sling to carry the baby up and down the stairs and fastenings on baby grows I didn't worry about too much.

And around about the time that I was expecting her was these new carry … baby carry systems had come into production. Baby seats that fit onto a pram frame?

Oh yes, yes.

So I thought, "Right, I'm going to get one of those and I went for the biggest, best one I could get which was a mistake, in hindsight, because it was a Silver Cross big heavy metal pram frame. Everything was big and solid but very heavy.

Yes. They're very bulky, aren't they?

The very early ones, they didn't really think about weight. It was just … they were very early models. So basically by the time I was due to have her I'd made this great big beanbag feeding cushion, I'd found a second hand table and sawn the legs off and recovered it to use as a changing table. I'd gone to a place that makes cots that have gate opening sides and had a cot designed and made for her. I decided that I was going to have full size changing mat and use that on the top of a the cot as a changing unit. I sort of thought of everything and been really prepared and thought, "Yes, yes, I can do all this."

And … oh and when I was about six weeks pregnant I facilitated a discussion group amongst thalidomide women. It was called something like Babies and Childbirth or something. And when we went round the group introducing ourselves, people were saying what their experiences were and nearly all of them that had had babies had ended up having emergency caesareans. I think only one of them had had a normal vaginal delivery. She'd ended up with really bad hip problems as a result. So as a consequence of that little discussion group I thought, "I don't think I want to go for a normal delivery, I want a caesarean." Talked to my consultant about that quite early on. I had quite a big list of all the reasons why I thought I should have a caesarean rather than go for a vaginal delivery and I said, "Right, if possible I think I'd like to have an elective caesarean" and I was all ready to start giving her the reasons but she said, "Yes, I don't think that will be a problem." "Okay." But I've since found out that she's actually really for caesareans because a lot of the work she does is with women who have had really traumatic births or who have lost babies in the course of giving birth. So she would rather give a woman a caesarean rather than having to deal with the aftermath. And she was lovely anyway. But she really was quite supportive.

But the problem is a lot of this doesn't echo down the chain so, you know, the consultant was brilliant but the staff with her aren't. So, for example, they'll say to you, "We need a urine sample. Here's a pot." And they don't give any thought to how I'm going to do that so I'd have to say, "Sorry but can I have a disposable kidney dish or something" and kind of come up with the answers myself.

Taking blood was another complete nightmare. You have to have a lot of blood taken when you're pregnant and you have to have your blood pressure taken all the time. Again, my GP was great. He said, "I'm going to get you a paediatric cuff and you can keep that with you so whenever you have to have your blood pressure taken you can just give them that and they can stick it onto their machine." Taking blood … I just became a bit of an expert at telling them how to get blood out of me. "Have you taken blood from me before? Right, you need two people; one of you needs to hold my arm like this. You need a small needle and blah, blah." I literally had to talk them through how to do it which is a bit disconcerting because these are people that take blood day in, day out. But if I didn't say that I'd end up with lots of stab wounds. And it tended to be more upsetting and distressing for the people trying to get the blood out of me than it was for myself. They'd get distressed at the thought that I was distressed but often I'd get distressed at their distress.

Then interestingly enough, they said from about six months, "We're going to have to give you steroids because there's a good chance you might have a premature baby because you've only got half a uterus." So I said, "Well, I'm a thalidomide baby so can you tell me about any side effects of taking these tablets?" And the answer I got was, "Well, you don't need to worry about the side effects because any side effects of the drug are far outweighed by the benefit to your unborn baby." That was the answer I got. I took these tablets home. I was told to take one a week for six weeks. Took the first one and the next morning my husband said to me, "Are you all right? You look really hot." I said, "No, I'm fine." He said, "Your face looks really red. You look like you're sunburnt." [Phone rings]. That might be Lois, do you mind if I …

Yes, of course. Yes.

Because there was a text earlier on, it might have been her but she should be home by now.

So, Simone, after you'd had your daughter, did the expectation of … you know, you had these worries about how you were going to change nappies and breastfeed and things like that. Did you find it more difficult or easier than you thought you were going to?

I don't think I had any kind of idea of how easy or difficult it was going to be. I just thought I was as prepared as I could be for doing what I thought I needed to do and how I needed to do it. I'd had a teddy bear and my sister and I had mucked around with this teddy bear in the sling and things. But, of course, that's not like a real baby. If it falls on the floor it doesn't matter. But I actually found it … I mean the first few days at hospital were awful because the hospital ward … I wasn't in a ward, I was in a little side room. It was tiny, cramped, I was hot. I was probably very hormonal. John, my husband, was staying with me. There was hardly enough room for him, he had a fold-up bed in the room but it was a tiny, tiny room so the bed had to be folded back up in the daytime. Lois was in a sort of one of these crib things but it was way above my height to reach and I'd had a caesarean so I couldn't get out and about. I had to rely on him to lift her up to me all the time. You just haven't got a clue what you're doing with this thing. I was just left to it. Because I wasn't on the ward with other women there wasn't any support or for me to see that they were struggling too.

And it was things like I didn't understand that because I'd had a caesarean my milk didn't come in straight away. So I was trying to breastfeed her on nothing basically and she was getting whingey and I was getting whingey and John was getting whingey. It was horrible. I just wanted to be at home and I knew at home I had this breastfeeding cushion that would make things much easier. Breastfeeding her on a bed that was really narrow when I couldn't hold her properly was terrifying. By about sort of the end of day two I'd sort of had enough really and the nurse said, "How about I take her into the nursery so you can get a good night's sleep and give her a bottle?" And I was, "Yes, yes." If she'd told me she'd take her away forever at that point I'd have been quite happy.

And then I did get a good night's sleep and then the next day I was told I could go home. And once I got home, everything was fine. I had my breastfeeding cushion, I got on the floor, the floor was clean. I mean the floor at the hospital was filthy, you wouldn't have wanted to put your feet on the floor let alone go anywhere near it with a baby. And because I was breastfeeding I think it was quite good because I was quite restricted as to what I could do and leaving the house was quite difficult but I was quite happy to be confined and it was November / December time so it was Christmas and there were a lot of people about to help and have cuddles and have her overnight and John was really a good dad and did everything that he had to do. He basically bathed her because that was really difficult for me. I mean you just think about slippery, wet baby and getting very wet yourself. But I'd got a bath above a big corner bath on a stand and that worked really well because I could actually sit on the edge of the bath, bath her and just let the plug out on the baby bath and it would empty into the big bath.

So it was all set up as good as I could manage and breastfeeding, once it was established, was easy and straightforward. I basically moved into the other room so I slept with her so if she woke in the night I would lie there and wait to see if she was really hungry or whether she was just murmuring so I wasn't just waking the whole household up. And she was a really good baby, she slept through the night from about ten weeks.

Wow.

Yes. Which I was really lucky about. And I really enjoyed being a mum; I really enjoyed the early days. I think it all started to get a bit more difficult when she became mobile and started to move around and I couldn't keep up with her. And, you know, she … they don't want to be in a pushchair, they don't want to be holding onto your hand and I suddenly thought, "Actually this is quite hard work now."

For example, going shopping with her, I'd take her shopping in the car. I'd have to ask someone to lift her into the trolley which I hated doing. I'd have to ask a complete stranger to do that for me. I'd have someone to go round the shop with me and then that person would lift her back into the car at the end. And they never minded but I did feel like, "I don't like having this help."

And then once I got home I'd have this baby that was hungry and needed changing and was crying and I'd have the shopping in the car and I'd be hungry and I'd need to go to the loo. But I just had to see to her first and leave the shopping and leave my own needs and leave my own food and I'm not the best person if I've not been fed. It suddenly starts to get a lot more difficult, even though she was a really good baby, slept lots, wasn't very demanding, quite a happy baby.

There was a particular incident when I'd taken her to the toddler group and up until then I'd put her in the pushchair to do the journey from the car to the hall and this particular day I thought, "I'll just hold her hand.” So we’d got into the hall, no problem, but coming out she just decided to break away from me and go running off in this precinct. And luckily it was a precinct and not a road. She just went running off down this precinct, she was only about two. And I thought, “Oh my God” and I went running after her and into the library and I chased after her and she thought this was a great game. She ran out of the library and I ran out of the library after her, we ran down the hill towards Asda and eventually I just thought I’m going to have to shout in a minute for someone to stop this baby. And then she turned around and started walking … running back to the car and with that my childminder, because I’d gone back to part time work, came out of the toddler group and saw us and said, “Is everything all right?” and I said, “Oh …” and she just grabbed hold of Lois and put her in the car for me and I just thought, “Oh, thank goodness for that.” And it was really scary and I kept thinking, “What if it had been a road? What if? What if?”

I got home and without thinking about it I just phoned up social services and said, “Look, you know, I need some help.” And they started basically trying to assess me on the phone, saying, “Well, can you feed yourself? Can you dress yourself?” And I was getting quite annoyed. I was saying, “No, I’m not asking for the help for me, I need it to be able to take my daughter out, you know.” And as I was saying all of this … I’d not chosen the best time to call because I was a bit upset from what had happened anyway and I could feel all this emotion welling up in me and I started crying on the phone and saying, “I just want to be able to take my baby out like most normal people do.” And John had been at home when I was making this phone call and he came in because he thought they were saying something to me that was upsetting me and I was saying, “No, no. It’s fine. It’s fine.” [Phone rings].

And so I realised, again, looking back on the event, what I’d actually been so upset about was that all my life I’ve never asked for help, never ever asked for help other than what most people would have considered would be normal things like a cleaner to help me clean my house when I worked full time. But having to admit that I wasn’t managing to do something which specially involved a baby that I’d chosen to have, was really difficult to actually admit that. So that’s what had caused me to get so upset.

But that’s amazing that you got to that point in life without having to ask for any help.

Yes, but I think because she was so good and because John had helped so much and it really was fine when I was at home … she was a good baby, she wasn’t into everything like some babies. And at home I’d got a big, like, what they called? Playpen. An old-fashioned playpen I’d bought second hand and I’d had that adapted by a company called … well, it’s a charity called REMAP who adapt things for disabled people.

REMAP?

REMAP. R-e-m-a-p. It stands for something but I can’t remember what. But basically you explain to them what it is you want to achieve and the outcome you want and they go off and do the work and they do it without a charge unless there’s an actual cost involved, so if they have to buy a part or something. But usually they’re the sort of people who have to have odds and ends in their garage but they’d adapted this playpen. So if I was having a shower in the morning, I’d just stick her in this playpen, even when she was really tiny, because I knew she was safe there and rather than try and make the whole house baby-proof which, because I’m so short, would have been more or less impossible, and she’d be quite happy because she’d always known that little playpen. But once I was out of the house that was frightening because you were worried that other people were judging you and you were worried about the way you did things being judged. So I might, at home, pick her baby grow up with my teeth but if I’m out and about, they judge it as being dangerous or, “Oh my God, that’s a bit animal-like.” But it’s fine in the confines of your own home but you can’t live in the four walls of your own house.

So they did agree to come out and assess me but they clearly didn’t have any experience of assessing disabled people that were parents and the questions and suggestions they were making were ridiculous, things like, well, “Can’t your husband give up work to help you?” and I was like, “Well, then he won’t have a job.” And things like, “Can’t you do your shopping online?” And at the time that was 1998, it wasn’t what people did and it was really expensive and I didn’t want to do it like that. That was my trip out. And things like I wanted to go swimming with her. Well I couldn’t take myself swimming on my own let alone go swimming with a baby.

So they basically agreed that they could give me some help and I kept asking about whether I’d have to pay for it and they kept saying, “Let’s get it arranged and we’ll worry about that afterwards.” And I had a visit from somebody from an agency who said, “I really want to come out and make sure that we match you with the right person so that this works” and talked to me about the sorts of things I wanted to do and the places I wanted to go. So we worked out a little schedule of the week and what I’d be doing when and then the first day this … there was a knock at the door and this woman turned up and said, “My name’s Stella and I’ve come to take your baby for a walk so you can have a rest.” I think she was Portuguese. I said, “No, you haven’t. You’ve come to help me do household things so that I can look after my baby. You haven’t come to take my baby off me.” And she was, like, “Oh, oh, well. This is not what I understood.” So I’d got this little schedule and I said, “Look, this is the little schedule that I developed with the agency and this is the sort of thing you’ll be doing.” So she looked at it and said, “Oh, swimming. No, I don’t do swimming. I haven’t got my swimming costume.” I said, “No, that’s just an idea of the sorts of things that I want help with. We don’t have to go swimming today. But, for example, today I thought you could empty the dishwasher and change my bed.” “Fine, fine. Just show me.”

She went upstairs and I followed her upstairs because she just stomped upstairs. And she was crying and I thought, “Oh my God, what have I done?” You know, “I don’t need this.” She was going, “I’m sorry, I’m sorry. I’ve just come from a house and the man was shouting at me. I don’t like this, I don’t need this.” And I thought, “I don’t need this.” And I still, at that point, didn’t have a clue whether I was paying for it. And this woman was … to be honest I’d never given it a thought about how long it takes me to do things so I’d been judging everything based on how long it takes me. So changing a bed might take me half an hour. It took her five minutes. Emptying the dishwasher might take me twenty minutes, it took her three minutes. So she’d done all these things on my list and she was going, “What do you want me to do now?” I said, “Oh, well …” She said, “Ah, it says peel vegetables. Where’s your vegetables?” I said, “Oh, they’re there.” She said, “I’ll make you a Portuguese soup.” So she got my whole week’s worth of vegetables and was, like, chop, chop, chop, chop, chop, made this enormous great big pot of soup and put all these spices in it and went. And I was left feeling a bit shell-shocked, thinking, “Well, God, what was that?” And I just thought, “There’s no way … that’s not what I want. I don’t want that at all.” You know, this is harder work than trying to do it on my own.

So I phoned up social services and, as usual, the person I wanted to speak to was on holiday so I said, “Well, I need to know how much this is going to cost. I might not be able to afford to pay for it.” So they said, “Well, the most it’s going to cost is this and you’re going to have to pay at least that.” And I said, “Well, I think the easiest thing is if I just cancel this because I said, “If I have to pay this, the top rate, I can’t afford to pay it. I can’t afford that much money.” They said, “All right then.”

That was that. There were no questions about was I going to manage or what was I going to do. It had taken me weeks and weeks and then weeks and weeks to set this all up and come out and assess me. They’d spent hours of their time and they just allowed me to cancel it with one quick phone call and not bother to ask me how I was going to manage without that help. And I just thought, “Well, I’m just going to have to carry on the way I was going really. She’ll be at school in another few years.” And I did have, you know, a supportive husband and a family I could call upon if I really needed to. And she was going to a childminder for a few mornings a week at that point so I could try and work. But what I was doing was doing all the things I couldn't do when she was here when she was at this childminders which was defeating the object because then I had to try and do the work I was doing at some other time. So basically I was paying for a childminder so that I could do my housework so it was a bit back to front.

So it was more difficult. I think why it was more difficult and what I hadn't really thought about was how long it takes me to do things myself. So I can get myself washed and dressed and wash my hair but it takes me an hour and a half and that's how long it takes, I can't do it any quicker and it does use a lot of energy. So if we both had to be somewhere at nine o'clock and it took me an hour and a half to get ready and it took me an hour and a half to get her ready then I would need to get up at some ridiculous time to get us both up and dressed and ready to go out. By which time, when we were both ready, I didn't feel like going anyway because I was exhausted and …

That's interesting actually. I hadn't thought about it like that in terms of the length of time to do things because I know as a mum myself I started doing everything really fast because you can only really get away with doing something that takes five minutes when you've got a little kid, can't you?

Or also you can do something like go to hang out some washing but you can do it one-handed with a child on your hip. I can't do that. I need both my hands and all my energy. And it does take me longer. So I can't think, "Right, I'll leave her there, she's happy playing with that toy, I'll be two minutes" because I wouldn't, I'd be, like, twenty minutes by which time she could have had an accident or wreaked havoc. But I was still trying to do it all. So I would get up really early before she was awake and do some jobs and she'd have … I was lucky because she had a big sleep in the afternoon but around the time it started to get quite hard work was when she gave up this afternoon sleep. I mean she used to sleep for three hours and that would give me the chance to get loads of stuff done. And I never, ever rested. I thought, "Right, she's asleep. I'm going to have a rest." I mean I'm not the sort to sleep in the afternoon but I didn't ever relax. I just kept going and that's a bit how I am anyway I discovered. I'm a bit like … I can't sit still for too long, I'm a bit of a fidget, you know.

And did you encounter at all, during those early years, any prejudices at all from other parents towards you being a disabled mother?

The only time I really felt like crawling into a hole was when I went to try out a Tumble Tots session and I phoned up and I asked them all about it and they said, "You just turn up on the day and enrol or you turn up on the day and you try it out and then you can enrol." So I turned up to this church hall and I got there early but the session before was already in progress and basically as soon as that session was finished, ours started. So there was no chance at all for me to talk to anybody and they sort of … they didn't welcome me as a new person. They basically said, "All come in and sit down on the floor." And I couldn't sit down on the floor so I went and got a seat and set it up and sat on that. And anything they did didn't take any account of me not being able to do things. And then they started, like … I don't know if you've ever been to a Tumble Tots session bit it's horrible. It's basically an army assault course with your child. And children just don't want to do things in the order that they're told to at two. If they see balloon popping they want to go straight to that over there. And they got most agitated with me because Lois started going on the equipment before the session had properly started and they were going, "We're not insured for her to do that." And I couldn't stop her because I couldn't climb onto it and get her off. So I just felt like … half way through the session I was just completely on my own, really struggling, really out of my depth. All of the other mums were sort of coping with their own child and I just thought … [Knock at the door]. I don't know who that is, you might have to … can you open it for me.

Yes, of course I can yes.

Tumble Tots story. So you were telling me about the Tumble Tots and you were left feeling very alone.

So I was about halfway through this session and it all just became a bit too much for me and I thought I need to get out of here. So I got Lois and I went into the toilets and I sort of half wanted somebody to follow me out and say, "Is everything all right?" But nobody followed me out and I was just sort of basically hiding in the toilet thinking, "That was just awful, that was awful." And I just went home and I thought, "I don't ever want to go back there again." I was made to feel so unwelcome.

And not long after that, because I wanted to do something with her, I found another contact for another little thing that was being run locally. I can't remember what they called it. A similar sort of thing. Gym for babies. I phoned up the woman and I explained what had happened at Tumble Tots and I just said I just want to be so sure that that doesn't happen again. And she said, "If you want to come to the next session, come early, you know, I'll chat to you." And it was just completely different. She was really nice, really welcoming, really nice with the children, talked to the children whereas the other place had been very much like women army instructors. At the beginning she said, "This is Simone and this is her daughter Lois and if anybody sees, you know, Simone struggling, can you give her a hand?" And it was just much, much nicer. Much nicer environment and experience and we did end up going there for quite a few months.

So it was just anything like that really. People not wanting to interfere because when it's your child … if you're carrying a heavy bag of shopping someone can say, "Let me give you a hand" and grab it off you. But people can't do that with a child and also I think they're a bit worried about, you know, being accused of anything when it comes to children, intervening at all when it comes to children. And also, quite often with disabled people, they might look as if they're struggling but actually they're managing in the way that they do. So it's actually me half expecting someone to notice that I'm struggling doing this thing and coming to my aid when, in fact, they think I'm doing all right. But again it's that thing about normally I'd say, "You couldn't give me a hand carrying this shopping out to my car?" It's very different to … "You couldn't lift my daughter out of this car seat and put her into this trolley?" which is sort of admitting that you're not a good enough parent.

Yes, I can see that.

Any woman might ask for help with lifting a heavy load but not any woman would ask for help to look after a child from a complete stranger. So although a lot of it was probably going on in my own head, it didn't matter to me. It was still the same end result. I was being judged and I was a lesser parent by admitting I was struggling and that people might be thinking, "She shouldn't have had this child if she can't do this thing" which is what people have to do for their children. Quite often mundane quite boring things like lifting them into a shopping trolley and lifting them out of a shopping trolley.

Things like we'd get to the checkout in the supermarket, when she got a bit older, and she would climb into the back of the shopping trolley and lift the shopping out and put it on the conveyer belt. She liked to do that. It kept her occupied. But, again, I used to think people will think she's doing that because I can't do it and it wasn't that at all, it was … that's just what she liked to do. And if somebody arrived and started unloading the shopping, she looked most indignant because that was her job and she was doing it and they were interfering. And I'd always feel the need to say something like, "Oh, you know, she loves doing this and it keeps her happy." I'd feel the need to justify why my daughter was unloading the shopping onto the conveyor belt, especially when it was, like, bottles of wine and gin and things.

So it sounds as though, in a way, you were quite sensitive to the idea that other people would think that you couldn't cope because you clearly were coping.

Yes. Yes. And I didn't have a child who was out of control, I didn't have a child who was, like, pulling down displays in supermarkets and things. She was a really well-behaved little thing. She wasn't screaming and having tantrums or anything. But I suppose it's … you know, a lot of it's … what goes on in your own head is another person's perception of what you know is perfectly under control and everything's fine. Or, on the other hand, when actually everything isn't fine but having to ask somebody to intervene and help you out.

Simone, I think we'll stop there for today because we've covered a lot of ground today. There's still a few more questions to go from this section which we'll cover in the next interview along with anything else that's left.

Okay.

Are you happy with that, to stop today?

Yes. Thank you.

Thank you very much.

That's all right.

END OF RECORDING