

Thalidomide: Sarah-Jane Gaitley (2012)

Ruth Blue interviews Sarah-Jane Gaitley for the *Thalidomide: An Oral History* project.

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*This is Ruth Blue interviewing Sarah Gaitley on 24 January 2013 at her home in Bracknell for *Thalidomide: An Oral History* and this is our follow-up interview.*

To start with, did you get the transcript of the first interview?

Yes I did and I read all the way through it from beginning to end, yes.

And did you have anything in it that you thought wasn't covered or wasn't covered as fully as you would have liked?

There was probably just one area about my dad and what my dad went through. I can't remember whether I mentioned that he'd had a nervous breakdown. I don't know if I ... I didn't ...

I think you might have touched on it.

Yes, but that was quite a significant point in our lives.

Okay, I'll put that into my questions for today. How did you feel, in general, reading back over your own words that you'd spoken?

I didn't realise that I'd said as much as I had. I was really surprised that it went to forty-three pages long in the transcript but I thought it was a good reflection of my life and how I felt about things and what life had thrown up, really, in my path.

That's good to hear. I had a few things that I wanted to ask you about. I put a note in to ask you about your father. But before that, if it's not too difficult to talk about, I did want to ask you a little bit more about what you were talking about with your mother's guilt about taking thalidomide which you did find upsetting.

Yes, I did, that's right, yes.

And do you think it's something, that feeling of guilt that she had, that's eased over the years or do you think it's stayed with her?

No, definitely stayed with her. It's coloured her whole existence and how she views subsequent events that have happened in her life. I think it all goes back to that one point of her taking that drug. It has definitely given her a bitter and angry outlook on events that have since landed on her, totally unrelated to thalidomide or my upbringing. But she does view things that happen to her as a curse and she does ... she is a very bitter and angry lady and it's very evident when she talks about other things in her life that that is coloured by that bitterness and anger still.

And she wasn't that type of character before ...

Well, I obviously don't know but she tells me she was a quiet person, quite a naïve person. She wouldn't say boo to a goose. That's how she describes herself to me. She had quite a large circle of friends when she was growing up; she was a popular person but she would always sort of stand on the fringes of the circle. She wasn't a leader but she was more of a follower but obviously when I was born and she had to be faced with dealing with doctors, consultants, solicitors, barristers, judges, all through the court case in the early 60s, she then ... well, she says that she's not an educated lady. She left school when she was fourteen and she went to work in a factory. She's not terribly good at reading and writing. I mean she can but they're not her strong points; she's actually very good with her hands and making things. So I think she felt quite intimidated with having to face up to these doctors and fight for her child and she found that quite intimidating. But in order for me to get the best help and the best treatment, she felt that she then had to speak up and be a bit more forceful.

The other things was that, I think I mentioned to you, when I was born and she first saw me, she said to me when I was a tiny baby, "I will make you independent if it's the last thing I do." I think some of her relatives felt she took that to extremes. They wanted to mollycoddle me and wanted to do everything for me. My mother's sister in laws and her brothers and aunts and uncles and so on but my mother wouldn't let them. If I fell over when I was a little girl, my mother would say, "No, she has to get back up. She has to know how to get back up." And she wouldn't allow my aunties to run and pick me up – bearing in mind, at that time, I'd had about four operations. I usually had big plaster casts on my arms and that's quite a heavy load for a little tot to take around with them and she was actually quite hard that I learned to do things for myself.

And the same cannot be said in how she treated my sisters when they came along because my next sister down, Louise ... my mum did everything for her – washed her hair, bathed her, cut her food up, fed her and whatever, whatever ... and she still does that to this day!

That's one of the peculiar things, isn't it? Because you often hear that you would tend to get more mollycoddled if you were ... but it's funny, I might leap forward to one of my questions because I really picked up on this about your mum saying she was going to make you very independent ...

Yes.

And when I was looking through some of your other answers you were saying ... there were a couple of anecdotes where you had to deal with things, mostly bullying from other children and you took it on board on yourself and you didn't ask for help.

That's right, that's right.

And you didn't feel like you could ask for help ...

No.

And I wondered if that was reflected back on the fact that your mother was trying to get you to be almost more than a normal child in a way.

Absolutely. Be independent and self-sufficient, yes, and she says even to this day that I am more independent than my other sisters. I know I am. I can see from what ... they're still at home with her, I've got my own family and responsibilities. But maybe I would have been that sort of person anyway, regardless of the disability. Maybe I would have been quite a strong character. I honestly don't know; how will any of us ever know? Because the circumstances dictated how I would react to certain situations. I can't say that I'm sorry that my mum treated me that way. I probably have to be grateful because I am able to live independently and look after and care for my own family which is something I always wanted to do. I always wanted my own family, always wanted to be a mother myself and have children so for that I am very grateful that I have the ability and necessary skills to be able to do that. Yes, I don't hold that against her and I don't see that as a bad thing but I know dad's two sisters, my two aunts, did see that as a bad thing and that did slightly colour their relationship with my mum. It was prickly at times, to say the least.

They thought she was too hard on you?

Yes, they did. In later years that was said to me more often, "Your mum was so hard on you when you were a little girl, making you do everything. We wanted to do it for you ..." but those two aunts ... one has since died, but they were caring for me throughout my whole life and I knew that they loved me deeply. They were, they were good aunts, they were lovely aunts.

And your mum was doing her absolute best for you ...

Yes, she was, yes.

She'd decided perhaps this wasn't going to be straightforward for you and she wanted you to be able to take it.

Yes, yes.

Okay, so let's talk now about your father's nervous breakdown because you've brought this up yourself as a subject.

I felt last time I maybe skirted that issue and didn't make as much of it as really what it was ... the impact it had on our family. I can't remember exactly how old I was, probably six or seven and I was aware that my dad wasn't very well, depression. I was aware that he was doing a lot of writing at the time. Once again, he left school at fourteen, he wasn't a terribly educated man and I felt the stress of the early / mid-sixties of going through the court proceedings and dealing with the judges and solicitors and having to write letters, he found that extremely stressful. He was lucky enough to have a local councillor; it was a Labour leader, MP, Ray Carter. Fabulous man, fabulous family and Ray Carter and his wife really supported my dad and the local Labour ... my dad was a part of the Labour movement in Bracknell and they tried to help my dad

as much as they could with the legalise and with the letters and putting my dad in touch with people that could help him. They were a great support.

But still, ultimately at the end of the day, that responsibility was still on my dad's shoulders and he took it really hard and he found the strain of it too much and my mum said to my sister and myself one day that we really needed to go back to London to live with my nan and granddad, my mother's parents, because my dad really wasn't very well and he couldn't work at that time and dad wanted to see a doctor, a family doctor that he'd had when he was living in London who he felt really comfortable with and we went back to live in Chiswick with my grandparents and my dad went to see this doctor and I believe was obviously given anti-depressants, and that, at the time. But my dad just didn't feel that he could cope at that time with living, basically. It was quite a rough time for him.

I think, as children, we were sheltered from a lot of that and all that we knew was that we were going to live with Nanny and Granddad and it wasn't a terrible hardship because we loved being with our grandparents and everyone that surrounded them and all the people that lived in London. But I think, obviously for my mum and dad, it was a very very difficult time for them.

They were sort of thrown out of what they'd expected their lives to be, weren't they?

Absolutely. Just turned on its head, yes. And the deeper they got into the court cases and having to attend meetings and meet people ... Lady Hoare came into their lives at that time and to meet Lords and Ladies, that was completely out of their world really, yes.

I can imagine how that would be very stressful actually.

Yes, that's right, yes. But dad did get over that, we did come back to Brackness after a few months and dad did resume working. I'm not sure if he changed jobs at that time to something that was a little bit less stressful but ... and he didn't seem ever to be right after that. There seemed to illnesses and things that kept cropping up. Not necessarily mental illnesses but he had a bad leg and it was terribly swollen and infected and he just seemed to be generally down quite a lot of the time.

But I feel, in later years ... I'd been married for six years when dad had his first stroke and this was back in 19 ... January 1998 and he went really seriously down, he never recovered from that and he had many strokes after that – diabetes, high blood pressure, dementia. The strokes caused dementia and he just couldn't come back from it. It was just too much. And he was in his early sixties when he finally passed away and it was far, far too young for him to go, it really really was. And I think all the early years had taken its toll on him and he just wasn't able to come back from the strokes and pick himself up again which is such a shame.

It's terribly sad, isn't it?

It is, yes. Yes, he was a lovely man, brilliant father, he did everything he could for me and I don't mean physically doing things for me, I mean opportunities. He made sure opportunities came my way and I took opportunities up and I made the best of each situation like that so yes, he was a very good dad.

It sounds to me, from everything you've said, your parents had an awful lot on their shoulders ...

They certainly did, yes.

But they took on board being part of the Society and involved with that ...

Yes, they did, yes.

And moved out of their comfort zone entirely and tried to set up the best possible future for you.

Yes, they did. Absolutely. Yes they did.

That's very good to hear. Now going back to your time at Roehampton. You mentioned that you ... you told me quite an amusing story about somebody offering you some prosthetic arms and you said, "Well, where am I supposed to put those?"

Absolutely, yes.

Whilst you were there and you weren't being fitted for limbs, do you remember what you spent your time doing there and do you remember any other children, without mentioning names, and any other stories from that time?

I do remember children. I obviously couldn't remember names anyway. But yes, I do remember thalidomide children. I remember doing lessons – we had a teacher and a classroom and we used to do lessons. I remember the TV room and I remember 1970 and the World Cup and Pele playing. I remember that quite clearly, a very, very hot summer – I always seemed to go in in the summer months and it was terribly, terribly hot in there. Playing outside on the little scooters and the little trikes, I can remember that. Seeing OTs, occupational therapists, I didn't realise at the time that that's what they were but they were trying to find adaptations and things to help me and to make life easier. And they did ... did I mention last time about the knife holder?

You did, and your husband made you a new one.

He did, yes. The first one was made at Roehampton out of Perspex and the OT there fitted me for that and moulded it and I went back for several fittings and so on. But they used to watch me get dressed and undressed and how I washed myself and things like that. Yes, that's about all I can remember. I didn't like it particularly and I didn't enjoy it, no. And I couldn't wait to get home again.

Being separated from family is not good at that age, is it?

No, it's not, no.

Okay. During your time at Roehampton, do you think that would have been the time when you first encountered other people affected by thalidomide or would that have been more at the Society events?

The Society events. That wasn't a great shock to go to Roehampton and see the others because I'd already met a lot of them before at the Society meetings, yes.

And do you have any recollection of how ... we did talk about this briefly about how you felt being out of the world of completely able-bodied people and in a world with children of varying disabilities ...

I can't remember thinking anything so, to me, that suggests I actually found it normal to be with other people like me. I didn't find it abnormal. I can't remember having any thoughts and feelings. It's just something we did and part of our lives and something ... I knew we had to go to this meeting or that meeting or we were going here this weekend or that weekend. I don't remember it being an abnormal thing. For me it was a normal thing to go and to be part of these meetings. I can't remember a lot of the meetings, there's one or two that stand out – a big house we went to once for a weekend, it was an old boarding school and we stayed in one of the rooms upstairs and I can remember the staircase and the grounds and we were actually friends with a family from Ascot at that time and they were there. And my mum was great friends with the parent and I used to play with the child who had no arms at all.

So I can remember that but there are not too many other memories from that time, no.

You described yourself as having had a happy childhood in general and great birthday parties, apart from hospital visits which you didn't like. But you said also that you didn't like looks and stares from other people ...

That's right.

That you had noticed that. And I wondered if there was a moment where you were aware ... perhaps you were too young, where you were suddenly aware that your body was shaped differently to other people and that's why they were staring?

I think it was probably ... first memory ... I think I was about five, I must have been going to school and I did have a discussion with my mum. I'm not sure if I told you this? I sat on the stairs in her house and we had a discussion about why my arms were different to everyone else.

I don't think you did.

Oh, right.

You did tell me about a moment when she told you about taking thalidomide ...

Yes, that's tied up with that time. I think I'd just started school but I don't remember my infant school being a bad place so obviously the stares, if they were, didn't bother me that much. I thought I was treated the same as everybody else and I didn't feel different. But I do remember having that discussion with my mum about my arms and why they were different and I think that's when she explained to me about taking a nasty drug and how they caused that when she was carrying me in her tummy, as you would explain to a small child at that time.

But I can't honestly say to you that there is a specific point where I remember being different. Obviously, as you get older, you get more aware of what is going on around you and I know, for a fact, that senior school was hell. I think I told you. And every day I would be called a name and somebody would have to make some comment about my arms. A lot of the time it was absolutely fine and I could brush it off. But just the odd times when it did get to you and I did feel burdened by it.

But I can't ever remember a defining moment, no. I think, over the years, I think you grow layers of skin and you push the stares and the looks back into your consciousness ... you're not conscious, back into your subconscious. You're aware that people are looking at you, even now, but I don't let it bother me and I don't dwell on it. I know it's happening but I don't physically think every day about people staring and looking. I'm just aware, in my subconscious, that's what's happening.

But it does ... obviously, my sons and my husband will notice before me, before I consciously become aware of someone staring. And my husband and my sons will take ... their backs will go up and they will turn round and stare at the person who's doing the staring, if it's in a supermarket or whatever. They probably notice far quicker than I do now because it's just a part of my life.

Yes. And there's different types of staring as well, aren't there? Most people stare at somebody at some point and try and work out who they are ...

That's right, yes.

But it's when it's staring that crosses a boundary of politeness ...

Absolutely, that's right.

It's different, isn't it?

It is different, yes. Yes.

Okay, thank you. We talked a bit about your father earlier with his breakdown but earlier you talked about his involvement with setting up the Thalidomide Society and was that something he remained involved with for many years afterwards?

Oh yes, up until his death. In fact, he had his stroke, first stroke, at a thalidomide meeting held at Runcorn in Cheshire. Then we were going on our way to the conference and dad had his first stroke in the car. The car started weaving all over the road and he'd felt poorly before we set off and said he had a headache and my sister and her then boyfriend, who then became her husband, were in the car with him and myself and my husband were in another car and dad got out and got into the passenger seat and my sister's boyfriend took over the driving but we continued up to Cheshire because we just thought dad was having a headache, a migraine or something, and never realised, until we got to Runcorn, that it was far more serious than that. And the then secretary helped mum get dad into a local hospital and that's when they diagnosed that he'd had a stroke. And when we came back we had to bring him back and put him in Royal Berks at Reading, the local hospital, and that was the start of all his problems.

Was it a major stroke?

Yes, that one was. Yes, that was a major stroke that time. He couldn't work again after that and his voice was slurred, he'd lost use of his arm and his leg. It was quite a bad stroke, yes.

And so obviously at that point he stopped being involved with the Society?

Yes, when I say he was involved, he wasn't a leader, no. He wasn't ... but he always went to the conferences and was always involved in that way because he was a timid ... when I say timid man ... he wasn't a loud man, he wasn't a forceful man but he did like to know what was going on and for us to be involved and to be around what was going on and to be aware of any new information that was available and so on.

Were the conferences very busy in those days?

Yes. I remember them being huge, lots of children, lots of children. Lots of parents. I think in those days it was very important for all the parents to get together and to discuss what was going on and what was happening regarding the legal side of everything. And they were obviously there to support one another – the most important thing.

Yes, because it was such an unusual situation to find yourself in.

Yes, it was, yes.

You talked a little bit about the Society holidays. Could you remember any more details of those – what sort of places you went to and ...

I think we went to the seaside one time. I remember going to ... I think it was Bexhill we went to at one point. And, as I said, this boarding school out in Buckinghamshire, I think it was a boarding school that we all stayed at. I went to London lots of times, various venues in London – lots of hotels and halls, meeting halls and so on. No, I really don't have any recollection of anything else. We went on the Trust Haigh Moor

Jersey holidays. We went together, as a family, several times to Jersey and then I went on my own, as I got older, with friends and family members.

Those were crazy holidays, weren't they?

They were, absolutely, yes.

I've heard lots of stories about that.

Yes, I can imagine.

Okay. Now you gave a few examples of what could be described as very clear disability prejudice when you applied for jobs early on before your mum intervened. Do you know how that made you feel when you were trying to get jobs and you were putting your best effort in but were being turned away?

Well I was upset. I felt that nobody was giving me a chance. No-one would give me a chance and I actually offered to work for free. I said to the interviewer, "I understand that you may wonder if I can do this job. I'm willing to work for free for a couple of weeks to show that I can." It wasn't taken up though, that offer was never taken up. But yes, it was just the thing of why wouldn't somebody give me a chance. Why couldn't I just show you what I can do? I've had all this education, went to college and passed these courses ...

Enthusiastic.

Yes. And it was just the fact people wouldn't take a chance, give me an opportunity.

When you were going through that, did you have anyone you could talk to about it?

Well I talked to my mum and dad about it, yes. They knew and they were as upset as I was that nobody would give me a chance and an opportunity. I spoke to the girls that I was at college with, at the time. We were quite a close group at college, all girls, in the business secretarial course, and some of those were finding it hard to get a job so I suppose I didn't find it ... I wasn't terribly out there alone on my own because everybody was trying to find jobs or going on to other educational opportunities and so on. I suppose I left college in the June and I didn't get a job until the following January so it ...

So that's six months.

Six months, yes. So it wasn't a long period of time to go without work but it was just the fact that when my mum did intervene at Sperry Gyroscope at that time, that then came to a head and I did then get a position.

So it took an extra bit of effort to ...

Yes, it did, it did. Somebody on the inside to speak up and say, "Well look, why can't you give my daughter a chance here? Get her to prove to you that she can do the job the same as anybody else. She doesn't need any special equipment. She doesn't need to be treated any differently to anybody else," and once we got over those hurdles, as I said, I was in that job for eleven years and went from strength to strength and ended up being a PA to the Chief Financial Accountant.

Exactly. So you did prove yourself. You talked at another moment in the interview about how you'd have really liked to have been a nurse if you'd had the chance. Do you think, if you'd been born with the same impairment as you have, today, you'd have been given more opportunities to do things like follow a career path like being a nurse or having a career in nursing.

Yes, I think probably had I been born today, with the same impairment, there would have been far more opportunities that maybe I might not have been able to be a nurse but I might have been able to have worked in the medical profession. Had I then followed an educational path that might have led me to one of those other career choices. But that's with hindsight I can say that now. It's easier to look back and say that. But maybe, yes, because Sue Kent ... she works as a masseuse and she's very good and she's worked at the Paralympics. I think that's outstanding that she can do that and it's a wonderful opportunity that she took and she ran with it basically and she won't be put down. I mean I won't, to a certain extent, but when I was told that nursing wasn't a good career prospect for me I didn't pursue other avenues because I didn't really know at that time what was open to me.

But I think careers advice today is probably far more aware and on the ball than it was back in the sixties and seventies. There probably are other opportunities in the medical profession that I could have pursued.

I think you're probably right actually, it would be different now.

I mean I'm really into psychology. I really absolutely love psychology and I often think is it too late to go back to college now and do a psychology course and with what I know now and the experiences I've had, the sort of things I could bring to that position ... is it too late at fifty-two to actually look at something like that and pursue it.

I think you're definitely not. I think the more maturity and life experience you have behind you the better.

When you talked, very touchingly, about Dale as a little boy and how he helped you a lot and you felt he had an instinctive understanding ...

Yes, he did. Absolutely.

I wondered ... we didn't really talk very much about his perceptions of you and your impairment and if it was ever anything that he's talked to you about or asked you questions about. Is it more his behaviour that he's adjusted or has he sat down and talked to you about thalidomide and any difficulties you might have?

Yes, we've had a discussion when he was old enough to understand. I told him why my arms were like this so he's grown up knowing why I've got arms like this. But it's not something he's ever dwelled on or brought up. But I do wonder how he's reacted at school with friends that have come home for tea and his university friends, now, when they meet me. He's never discussed that with me but I think that he does prepare his friends, and so on, to say that his mum is disabled and she was born thalidomide, just to put their minds ... make them aware before they meet me. Now he has never ever told me that that's what he does but I just get the feeling that he's such a perceptive boy, that he would want me to be at ease and he'd want his friends to be at ease. And I've always had a really good relationship with his friends from school; we always had someone coming around for tea, he's brought his university friends back up here now, they've stayed for the weekend. There's never been any problems, you know, everyone accepts me and no-one's been staring or anything like that so I think they're already clued in before they meet me as to what is what.

Well you'd be able to see, wouldn't you, a change of expression if they come in and go ... oh, I didn't know ...

I think they've ... like the chaps that have stayed here over the weekend, they're quite curious to see how I do things in the kitchen when they've been sitting at the table out there and I've been preparing a meal. I can see ... I can feel them watching me but they never say anything, they don't bring it up. But they're probably ... I'm not sure if I should say this but they are quite amazed at how I can do things and it's not a big deal and I don't need extra gadgets and I don't need extra help. I just get on and I prepare a meal and all the rest of it. Yes, so ...

But it is interesting. It would be a lie to say it's not interesting to see how somebody with a differently shaped body does the things that you take for granted.

Yes, absolutely.

And I think probably that was one of the things that was good about the Paralympics. If you said to most people, "Somebody with no arms can win a swimming race" they'd say, "How?" How is that possible?

That's right and how do they actually go about physically doing it? How do you go about cutting up vegetables and things like that. Until you see it and you think, oh yeah, that makes sense!

And you don't mind that kind of interest.

No, no, because I accept that that's normal, that's normal curiosity. No big deal is made out of it. So yes, I got on well with all Dale's friends. But he is a very perceptive child. I'm not quite sure how Aidan has handled it, actually, because we have a lot of his friends here ... although a very interesting thing happened a few weeks ago. We went to Aidan's school for a parents' meeting and we were in the lounge having tea and coffee and one of the boys at the school came up to me and said to me, "Can I ask you how your arms were formed that way?" I said, "Well they were formed that way because of a drug called thalidomide." "Oh," he said, "Okay then." And he went away and he was quite happy and he did not stare, he just wanted to know why. And the other parents around me immediately felt embarrassed, I could feel it. But I didn't feel

embarrassed because he was a young chap with autism and he wanted to know why I was different to everybody else. And he did it in a very direct, straightforward way and there was no nastiness attached to it, or stupidity attached to it. He just wanted to know, that was fine. I told him and he went off on his way.

But I'm not quite sure how Aidan ... if he has prepared his friends or whether ... I'm not sure.

It's probably more difficult to try and get into his mind ...

Yes it is, it is because he doesn't have the verbal skills to be able to say to somebody why his mum is like that.

Has he ever spoken to you about it?

No, but I have told Aidan ... I did tell Aidan, when I felt that he could understand the whys, I did explain to him and he doesn't talk about it much, no. He doesn't ever say anything about it. But if he sees me struggling doing anything, "Oh come here let me do that" and he'll jump straight in and if I can't do the zip up on my coat he'll do it, "Let me do it." And he doesn't make any issue about it, you know, he just gets on and does it.

That's sweet.

It's very sweet. Both my boys ... yeah, they are brilliant.

They sound lovely, yes.

They are brilliant young me, yes.

They sound like you've done a good job with them as well.

Well, as you said earlier, they've been brought up in a family with disability and issues and they are more aware of the world around them and of people being different and us not all being the same. And it's broadened both of their outlooks. Even Aidan, with such a limited understanding, even he has a broader range of what is right and wrong and how you should treat people and so on, definitely.

And I think that idea that just because something's different it doesn't really matter.

No and it's not wrong. If it's different it's not wrong.

Exactly. I think that's very important.

It is, yes.

Going back to that idea of defining a moment when you first felt disabled. You did define a moment when you said over the last ten or fifteen years you've experienced more problems with your body and that you have suddenly felt like a disabled woman for the first time ...

Yes, that's right.

And do you think that's purely down to physiological things going on where you've suddenly felt you can't do something ...

That's right, absolutely. I've slowed down an awful lot and I know I can't do all my housework in one day like I used to do. Just cleaning the bath and I'm finished and I get upset because I think I can't do anything else today and all I've done is clean the bath. But my back is breaking in half and because it's spasmed and seized up, I then have to go and lay on the bed for two hours. As I told you before, I don't like taking pain killers. I don't like taking pills of any description. So, for me, the only option is to rest and that makes me feel like a lazy person because what am I doing? I'm at home and I'm laying on the bed. But I can't get up and physically do anything else so that makes me feel disabled, yes.

So more than the way you were born, because you always found a way around that ...

Yes, I did, yes. Absolutely. Where there's a will, there's a way. My mantra, yes. It usually still is – where there's a will, I usually will do something and I will get round it. But there's some times that even my endurance can't get round it. My stamina's just not great any more and I can't battle through it any more.

And do you get support from your husband in relation to that changing level of what you can and can't do?

Sometimes, yes. But my husband is a male. With the best will in the world, he's got a male mentality and he doesn't always see things that you think he should see or respond accordingly. If he's at home he will help with the housework if his shift pattern allows and we aren't having to do anything else or run anywhere. He will definitely help with the housework. He probably doesn't get involved in too many meal preparations. He generally leaves the meal preparation to me which I do get annoyed about. I think you're sitting in there watching the television, why can't you get off your backside and help? But I think that's a typical wife's observation there that all the husband is interested in is watching the TV and he doesn't think to get off his backside because he sees me as quite a capable person ...

Well, you are ...

Most of the time, 99.9% of the time he doesn't see the disability.

No, of course not.

He doesn't even think about it. That's why he wouldn't ... but if somebody else was in the house from outside and I was in here preparing a meal, they'd jump up and say, "Oh, is there anything I can do to help?" and my husband would probably look at them and think, "What you doing that for?"

Why does she need help? She's fine!

She's getting on with it, as always. So, in a way ... it's strange. In a way he's behaving like a normal husband, treating me as a normal wife ...

Which is what you want.

Absolutely. And other times I get so tired I think, "Why can't he just see that I need help?" But then I don't ask him for help. That's my problem.

That's your independent streak again, isn't it? I'm not asking for help.

Yes, yes. I might be standing here tired, and my back is killing me, but I will get this meal on the table, come what may. But that is my fault, that is my problem.

Well you say it's a fault and a problem but in a way it's really allowed you to be very successful in your life, to have a successful career and raise two lovely boys. And in a way, if you did give up more easily perhaps you wouldn't have achieved these things.

Maybe not, that's true, maybe not.

Okay. That's actually the end of my questions because we've covered all the things I wanted to ask you. But is there anything that you would like to say? We talked about how you feel today, in general, about how thalidomide affected your life ... we talked about that before ...

Yes.

And really how you felt as though it had possibly had even more of a profound impact on your parents' lives than yours in terms of changing the course of their lives. Is there anything else you'd like to say about that, about looking back or anything that you ... apart from being a nurse, is there anything else that you would like to do ...

I think probably from the boyfriend angle, I wished I'd had an opportunity earlier to have relationships. Just meeting Trevor and him being my one and only, I missed out on lots of stages. I had to jump in at twenty-six, into an adult relationship, having not gone through the teenage years of relationships with boyfriends and sexual encounters and that type of thing. So I found that quite emotional at the time and difficult to handle, to jump straight into an adult relationship with a man who was nearly thirty and obviously was not a teenage boy but was an experienced man.

And that was a learning curve for me. I had to learn everything in a short space of time that usually you would learn in the space of your teenage years. How to deal with the opposite sex and how relationships were supposed to go and all the rest of it and what was expected of me and so on.

So you missed out on some of those normal teenage developmental stages.

Yes, yes I did. Yes, definitely. I can remember my first kiss with Trevor because that was the first time a male had kissed me and I was twenty-six years old and it was a really emotional ... it wasn't a passionate kiss, we were just saying goodnight on my mum's front doorstep but I went ... I was in a daze because it was the first time I'd encountered that relationship and I can remember that kiss really well because it wasn't really that long ago and it was a big deal for me. Yes.

I suppose that's one of those things you don't really think about unless somebody says it. So you could see lots of your friends doing different things but you were ... without them excluding you, you were outside.

I was definitely, yes. That tore friendships apart at that time because I was then getting left behind and that was the first time ever that I felt different and I actually was getting left behind by my peers because I wasn't having the same relationships and opportunities as they were. And I had to wait until much later to experience all those feelings.

And so you never did meet a boy who was interested in you at that period of time?

No. No-one at all, no. We went out as a group with boys and girls and gradually, obviously, those boys and girls started to pair up in that group and obviously I was left on my own, yes.

What about fellow thalidomiders? Was there no hint of romance with any of them?

No, none at all, no. I didn't see anybody on a regular basis in order to form any relationships like that. There aren't too many around this area. There's one in Ascot and one in Reading, who are both female but I don't know of any other males around this area to be quite honest. And if I went to the conference once a year, that was it. Just a weekend away and that was the end of it, yes. So there wasn't an opportunity to form any attachments.

Thank you for telling me about that. And is there anything else that you think you would have liked to have said?

Oh goodness, I don't know. I don't think so. I can't think of anything.

You don't have to if nothing springs to mind.

No, nothing is springing to mind at the moment.

I think you've given a very full and clear picture of your life and your parents and your career.

I think, despite all the staring and the hospital visits and obviously losing my dad too soon, it generally has been a good life. I've had lots of good opportunities, lots of good opportunities to travel and do things that other people have done. So I don't feel as if I've missed out on too much in my life.

I went to a school reunion a couple of years ago and I was looking around at some of the people I went to school with and one lad, in particular, well he was a man, a grandfather by then, he asked me what I was doing. I said, "Well, I'm married, my husband works at Heathrow, I've got two sons, one's at university" blah-de-blah. He said, "Oh ... on." I looked at him and I said, "I'm not doing too much differently to you, am I?" And I think he expected me to say that I was at home and I didn't do anything and didn't go anywhere and hadn't had a family but when I looked at myself in amongst all these people, I was exactly the same as them, I had done nothing different to them. In fact, I'd probably been on a few more expensive holidays than they'd been on, a few more opportunities to travel the world. I had a lovely brand new car out in the car park. I've got a lovely home.

So I consider myself, in those respects, to be a very fortunate person because life could be a lot different. It is a lot different for an awful lot of people out there who don't have disabilities. And for that I am grateful that I have had the life that I've had, that I'm happy and secure and healthy, reasonably healthy at the moment, I don't mean no nasty illnesses or anything. And that's all I pray to God for each day, to remain healthy and happy and to be able to be there for my family and to wake up every morning.

Those family moments are lovely, aren't they? Priceless.

Yes.

Do you think ... just thinking about this on the spot from something you've just said, have you ever become aware of there being any bitterness or resentment from other disability groups towards thalidomiders because of issues like getting compensation and more help with money than possibly other disabled groups get?

Not particularly, no, I haven't. But I think that comes ... I think my sisters and the one sister in particular is resentful that I have got excess cash to be able to do expensive holidays and have nice cars and I think she finds that hard to deal with – that I've got a disability but I can sit at home on my backside, I don't have to work. I can afford to drive a lovely car and have a nice home and I think that is a huge part of her resentment towards me but I can't say I've encountered that from anybody else. It's never, never come to my attention, no. I'm not aware.

Because a lot of people describe people affected by thalidomide as being a different group to ...

Yes, I do realise that and I do have to say in myself I do think we are a special, unique group because of what happened to us. And that's why I do a lot of my fighting in the local community for other disability groups and stand up and speak for the. And I feel it's important when I go there to these meetings that all disabilities are recognised and there's help for everybody. That's a big part of my voluntary work, speaking up for people ... well, especially children, with all disabilities and conditions and syndromes. Everyone finds it hard and they all need help with Social Services, education, health. And they're all battling ... I can identify very easily with all of that.

And it's interesting thinking that if your life had been different, you wouldn't probably have been so involved with that and helping ...

Absolutely.

Those people, would you?

That's right, I wouldn't. I wouldn't probably have the understanding from a child's point of view and the parent's point of view. But seeing as I've got Aidan with the disabilities I probably would have had the same sorts of issues. We had to fight to get Aidan special education and to get the right services. I do think, compared to a lot of the parents that are on our groups and so on, forums, I have got a very unique perspective of coming from both angles and I try to help parents be more positive about their children's outlook because my parents didn't know, when I was born, how my life was going to go and what I'd be able to do.

And when you look at the children that are in wheelchairs now and have autism and all different types of conditions, their parents think they're not going to be able to do anything, they're going to be in a home but you don't know that. You do not know how they're going to progress, what help will be available. Things are getting better and better all the time. They've improved over the last fifty years enormously. This is completely different to what my parents went through and I am able to point that out and to make them think that there is another side to this, it's not all doom and gloom and it's part of my job to provide another side to the issues and to help them speak up if they're a bit timid, "Oh, I can't speak to a doctor." I said, "At the end of the day, he's a human being. He might be a doctor but if you don't feel your child is getting the right help you have to say so. Your child can't speak, you have to. It's only you, at the end of the day, that will help your child progress. You can speak up to get the right help" and so on.

So I hope in some way that I can help other parents, you know.

I think that sort of parent's reaction to a disability or whatever is so key in terms of how that child's life is going to pan out.

It most definitely is. Absolutely. If you're a parent that's going to sit back and not get involved and not push your child forward and not get the right help, then that child isn't going to make much progress. It will just get what it's given and that will be the end of it.

It's like parents that are told they have to go to our local special school. Well no, at the end of the day, you don't. There are options out there. You have to get off your backside, you have to find these other schools, go and visit them and see if they are the right school for your child. Can they help your child progress better? Can they offer more facilities? But you won't get that if you don't go and look.

If you give up before you've started.

Exactly. Exactly, yes. Don't settle for less when more can be out there if you just get up and do something about it.

I agree with you.

I get on my high horse.

No, it's very refreshing to hear this independent streak in you and you've obviously picked up a lot of that from your mum, even if she had to learn that along the lines.

Okay, well, that's a great not to end. Strident Sarah.

If you do think of anything or anything comes up that you'd like to add, you can always get in touch and I'll obviously send you the transcript through from this. The other thing is we would like to use some extracts from some of the interviews in our presentation at the AGM. But we'll be sending a copy of all the extracts we'd like to use to you to approve.

Okay.

You can say if you don't want anybody to listen to that part. So it will be small parts that we'll be putting together as a compilation. Lots of voices talking about mothers, lots of voices talking about medical intervention so we get a really nice full picture of all the different experiences. So would you okay about us using some of your interview?

Absolutely, yes.

Great, so I'll be in touch with you about that as well. We're hoping to make a 20 minute – half an hour presentation of just voices so I think that will be quite moving to hear.

It will be, yes, absolutely.

Okay. I think we're done.

Thank you.

Thank you so much, it's been a real, real pleasure talking to you and you've given me lots of things to think about as well.

Okay.

END OF RECORDING