Thalidomide: Sarah-Jane Gaitley (2012)

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

This is Ruth Blue interviewing Sarah Gaitley on the 15 November 2012 at her home in Bracknell for Thalidomide: An Oral History. Sarah, can you confirm that you've signed the copyright and consent forms?

Yes, I have.

And could you just tell me your full name, age, date and place of birth?

Sarah-Jane Gaitley, age fifty two, date of birth 11/07/1960, place of birth Wokingham, Berkshire.

Okay. So in the first interview really we'd like to hear about your childhood, your birth, your family life and early school and medical interventions, beginning with your family background.

Yes.

So your parents, what line of work they were in, and your brothers and sisters.

Okay. My parents were June and Bill or William Higginson. They came from Chiswick in west London and they moved down to Bracknell in 1956 and I was born four years later in 1960. My mum didn't work at that time but my dad was an engineer with Ferranti working on gyroscopes.

Oh, wow.

Yes, so that was his job at the time. My mum did get a job, part-time job and she worked in engineering as well, she worked for local companies in Bracknell. So she worked on an engineering assembly line after my second sister was born, I think she went back to work.

So are you the oldest sister?

I am. Eldest of three girls. I've got a sister that's two and half years younger than me, her name's Louise and I've got another sister, Frances, who's eight years younger than me.

So a family of girls.

Yes, yes.

Okay. And moving on to think about the drug thalidomide, do you know who prescribed it for your mum?

Yes, it was a local GP practice.

And what was it prescribed for?

Morning sickness.

Do you know how long she took it?

She said she only took two or three tablets so it wasn't a length of time but she doesn't remember exactly what day, week or month that she took it during the pregnancy, she's not sure.

Did she have very bad morning sickness do you know?

Yes she did, yes. She felt very poorly and she felt very tired. I think the morning sickness lasted all day and left her feeling very weak and that's when she went off to the doctor's, yes.

Yes. It's very different these days isn't it? If you have that morning sickness they don't give you anything.

Absolutely. That's right, yes.

So do you know if they had any worries about you using a drug during pregnancy at that time? Did they just trust the GP?

That's right. My mum didn't have any concerns at all. She didn't know that any drugs could affect the baby or whatever. She had no knowledge of that whatsoever at that time.

And apart from the morning sickness do you know if she had a good pregnancy?

No, it wasn't good. After she'd actually taken the drugs her hands and arms began to swell. She had pains in her legs, she couldn't walk. In the mornings she said her hands were like claws and she couldn't open her fingers and that was after taking the drug and she had high blood pressure as well. So she had quite a rough pregnancy.

Has anyone ever suggested that those things she was feeling were possibly a side effect of thalidomide?

Not at that time, but yes later in years she then began to realise that it was the drug that was causing all these other side effects for her, in her arms and her hands and her legs and her feet, yes.

Yes, because it does affect the peripheral nerves, doesn't it?

That's right, yes. Exactly, yes.

Yes, of course nowadays if she'd had that effect somebody might have thought, "Is this a side effect of a drug?" mightn't they?

That's right. Absolutely, yes.

Is it something you've been able to discuss with your parents, about the decision to use thalidomide. Were they able to speak openly about it, or was it difficult?

It was difficult but yes, we have always spoken about it. I knew from a very early age, I think five or six, that my arms were different to everybody else's because mum had taken a drug so I actually do remember the day that my mum and I spoke about it and we sat on the stairs in my mum's house and I'm not quite sure what provoked the conversation but I do remember her telling me why she took the drug and she didn't know that that's what it would do and that she was really very, very sorry. And I do know that she carries the weight of the guilt today, still, and probably apart from everything, that affects me the most, is her guilt because I do not hold her responsible whatsoever. She is as much a victim as I am and she went through hell as well. As difficult as my life has been she has gone through it every step of the way with me. And I do wish that she would absolve herself of the guilt, I really, really do. That would be my one wish. [SG becomes upset].

Do you want to stop for a minute or are you okay?

Yes, please.

[Break in audio].

Sarah, moving on to talk about your birth, do you know where you were born?

Battle Hospital, Wokingham.

And has your mum ever told about what the birth was like?

Yes. She says that it was very painful. She had to have an incision because my arms were folded back onto my … my hands were folded back onto my forearms which was actually stopping me from coming down the birth canal so it was actually quite a difficult birth for her and she realised as soon as I was born that something was wrong but the staff didn't discuss with her what was wrong. They bundled me up and took me away immediately and then my mum was taken to a side room and left. My dad wasn't there at the time because this was at nine o'clock in the morning. He was at work and the hospital then phoned my dad at work and said, "Your child's been born but you need to come to the hospital immediately" and he was called and he was then shown me. And my dad then went in to see my mum and my mum said, you know, "What's wrong, what's going on?" And he said, "Our baby's not normal, there's something wrong with her arms," he said, "They're folded back and they're not developed as they should be." And my dad said to my mum, "If you don't want to keep her, we don't have to keep her." And my mum said, "Well I want to see my baby" and the nurses then brought me into her and apparently my mum looked at me and she said, "I'll make you independent if it's the last thing I do." And I think she would probably agree that she did a very good job and I'm probably too independent for my own good because I find it extremely hard to ask for help and I rely on myself and my own way of doing things. So from that point of view she did an extremely good job.

Well, that attitude has probably made a lot of difference to your life, having that attitude so early on I would say.

Yes, yes. Yes.

Okay. So your parents were aware that you'd been born impairment fairly early on after the birth. Because this is an audio interview can you describe your level of impairment?

It's my arms and hands. I've got my radius bone missing in both arms.

So this bone.

That's right. And my hands are turned inward and I have four fingers and no thumbs.

Do you know if your parents were given any immediate medical advice after your birth?

No. My mum was in hospital for nine days and apparently the GP of her practice was informed about my birth, a Dr Alexander, and he asked a plastic surgeon that he knew to come to the hospital to see me to see if anything could be done and apparently he did this. But my parents weren't told of this until later; my mum had no idea that a plastic surgeon had come to see me and apparently the result of that meeting was that the plastic surgeon said to my mum's GP, "This child needs an orthopaedic surgeon, not a plastic surgeon," he said, "And I think you ought to refer this family to Great Ormond Street to a Dr Lloyd Roberts" which the GP did do.

And did you go to see him?

I did, when I was three months old. I was taken to Great Ormond Street for the first time. Great Ormond Street apparently asked my parents had I been Christened at that time, at three months, and my mum and dad said, “No.” And they said, “Well we can do it here at the hospital or you can go away and get this done but your daughter will need operations on her arms and hands to help straighten them” and my mum and dad did get me Christened fairly quickly and I went straight back into hospital and had four operations, two on each arm, to straighten them, to break the bones and to straighten the arms.

So did they break … which bone did they break? Where did they …

I’m not sure. But when I was a baby and when I was little they were completely straight. I had two operations. I’ve got scars going down the back of the hand and arm and I’ve got scars on the hand going into the wrist area, stitches there. And I was put into splints and plaster of Paris which probably lasted for two years on and off, going backward and forwards to have plaster of Paris and splints and I wore my splints up until I was about five or six when I went to school.

And do you think … I know it’s probably hard to imagine but if you hadn’t had those interventions do you know what shape your hands and arms would be now, what difference it made to them?

Actually they would be … I think my arms … since I was discharged from Great Ormond Street when I was sixteen … so all medical interventions stopped at that point and I noticed myself then that my hands began to grow back because I wasn’t given any physiotherapy, hand exercises, splinting had all stopped. So my hands, of their own accord began to grow back so I presume that my hands [SG demonstrates] …

Would have been twisted in that direction.

Yes, would have been twisted in that direction so obviously would have been very hard for me to have picked anything up or hold anything. So the straightening of the hands at that time did help me achieve a lot more. I could actually do a lot more things when I was a child than I can actually do now. Because my hands have grown back round I can no longer get my hands behind my back and touch my fingers together. As a child I could do that.

That’s interesting.

I could reach further areas on my body than I can reach now and I was fairly independent as a child, probably more independent than I am now as an adult, yes.

That’s interesting to hear actually. So, if they’d continued physiotherapy at the age of sixteen, do you think you might have actually got quite a lot of benefit from that?

I think I probably would have done. I do remember the last appointment at Great Ormond Street my mum was asked, “Would I like to be transferred to a hospital in Carshalton?” And she said, “No,” because the doctor advised her there probably wasn't anything else that could be done at that time and mum said, "Well what would be the point then of going," if there was nothing more they could do, so she didn't take up that offer at the time.

Okay. So do you have a lot of recollections of those hospital visits?

Not from when I was very little, not from the operations. I can remember going to Great Ormond Street for follow-up appointments in later years. That was a day's outing. My mum was very good. She didn't make it into a hospital visit but a day's outing to London. We used to go on the train and the bus and we'd take a picnic and there was a small park near Great Ormond Street, we used to go and have some lunch and feed the pigeons and the birds. So for me it was a day off school and it became an outing rather than a hospital visit.

Yes. So you don't remember them as particularly painful experiences or …?

Not painful, no. No. When I think I was about eight, between eight and ten, my mum and dad had become involved with the Lady Hoare Trust and I was given a social worker, Lillian Ramsey. Absolutely super lady. My family can't thank her enough for what she did for us. But she got me into an assessment programme at Queen Mary's Hospital, Roehampton, and I used to go to the children's ward, just once a year for three or four days to have an assessment. And I didn't like it and I do remember clearly going and I used to go in on a Sunday afternoon and every Sunday night I would throw up because I didn't want my mum and dad to leave me and I didn't want to be there and I used to stay 'til about the Wednesday or Thursday and they would come and pick me up and bring me home. And I'd see various doctors, occupational therapists, physiotherapists and obviously meet other thalidomiders that were on the unit at that time, yes.

Yes. Are they people that you still know now?

Yes. Yes they are, some of them, yes.

It's amazing how many children got to meet and congregate at Queen Mary's actually.

Yes, yes, that's right.

So would it have been Doctor Newman that you saw, Claus Newman?

It probably was, I don't remember specific doctors. Though saying that, one doctor who I can't remember his name asked me if I wore artificial limbs, "Do you have artificial arms?" I said, "No, where would I put them?" because to all intents and purposes I had arms and hands that worked and I thought this was a very strange question. I was only a little girl at the time but that does stay with me and I do remember that very well.

And they never tried to offer you or persuade you to use artificial arms?

No they didn't, no. They gave me another gadget which I still have and use today and that was a knife holder. At that time it was made of Perspex and it went around my hand and it had a little slot for the knife to go into so that I could hold the knife and be able to use pressure to cut things up and I still use that today.

The same one, or a new version?

No. I've got a new version … well, a new version, yes. My husband, he was a sheet metal worker, and he made me stainless steel clips, as we call them. When I got to meet him, this Perspex one by that time was getting very tight as it had been made for my hand when I was quite young and he said, "Well, I can take that as a template" he said, "And I can actually make you one out of stainless steel" which he actually made three or four at the time and we distributed them around the family so I didn't have to take them wherever we went.

What a fantastic idea.

Yes, yes. We've got two here, one at my mum's, one at his mum's, so … yes. He had his uses.

That's fantastic actually. Okay. So straight after your birth you came home?

Yes. I did, yes.

And you didn't, at that time, have any siblings because your sisters were yet to be born.

That's right, yes.

Do you have any idea, you know, probably through your mum because obviously you wouldn't remember, how your extended family reacted to your birth, if your mum was offered support?

They were … the rest of the family lived in Chiswick still, my mum and dad were in Bracknell, but they were fantastic, my mum's family in particular. My dad's mother had died by that time and his father was no longer on the scene but my dad's two sisters, Josie and Kitty, were an absolutely tremendous support for my mum and my dad. They were all shocked, as well, it was a complete shock for them but they gathered around my mum and dad and even as a very, very small child I knew their love and support as well and I grew up with that love and support around them and around me and that was extended family, aunts, uncles, close family friends from Chiswick. They really did cocoon us, my mum, dad and me, with love and support and I didn't feel anything else but love and support from all these people.

That's wonderful to hear.

They were absolutely brilliant, absolutely brilliant.

It's absolutely wonderful to hear that. So would you describe yourself in general as having had a happy childhood, would you say?

Yes, from a family point of view, yes. It was happy, yes. I remember lots of parties because my birthday was in July. My mum and dad always made a fuss of my birthday and invited the whole family and we used to have some fantastic parties in the garden with the long, hot summers in those days and everyone would come down from London to Bracknell and they were really lovely times, really lovely times. Lovely family holidays away and the whole family, the extended family, would go to holiday camps, Caister in Norfolk and Pontin's holiday camps and things and I grew up with my cousins very closely, yes, so it was. It wasn't so happy from the point of view of external influences as in going to hospital visits and stares and looks from outside people and bullying from school friends and peers. That side was difficult.

Let's go on to school in a minute. In terms of the growing knowledge of thalidomide that was going around, do you know at which point that your parents realised that your impairment had been caused by your mum taking thalidomide?

Apparently I was about two / two and a half and there was a lot of reports in the papers, the newspapers. My mum and dad then started to wonder. My mum went to the doctors and she spoke to one of the doctors in her practice and said, "Is my child one of these thalidomide babies?" And it was a Dr Mary Medhurst who said, "Yes, I'm afraid she is." And apparently the next night my dad went to the GP practice and actually demanded to see the doctor that had prescribed the drug, who was a Dr Alexander, and my dad attempted to throttle the doctor.

Oh dear.

It was a very unpleasant affair and my dad was very, very upset but from that point, once they'd got the recognition from the GP practice that my mother had been given thalidomide, Dad wrote to John Pilger at the Daily Mirror and asked to be put in contact with these other parents. That then was the beginnings of the Thalidomide Society. My parents were in on the very early days of setting up the Society. They were actually given the name of Peter Carter and my dad went to a meeting, my mum didn't go but my dad went to a meeting with Peter Carter and several of the other parents to see where this was going to lead and they formed the Society, then the Thalidomide Society.

That's amazing to hear, actually. I didn't realise your dad was so involved in the early days of the Thalidomide Society. Was that something that as you grew up you were aware of, going to Society meetings?

Absolutely. Absolutely, yes. We went to weekends away, we went to conferences and I got to know lots of the other thalidomide children at that time and we all used to play together. It was probably a bonding experience of getting to know other people and you didn't feel that you were the only one and that there were other people that were similar to you as well.

Yes, I was going to say to you, how did that feel to suddenly have a new extended family if you like, of a sort of a peer group?

It was good because it didn't make me feel isolated anymore because in my primary school I obviously was the only child with a disability and that made me feel very alienated. So to actually go to the meetings and the group gatherings was good for me to see other people, other people worse off than me. It made me look at myself and realise and be thankful for what I had and that I had arms and hands, they might be different to other people's but at least I had legs that were really good and strong and I appreciated then that my disability, you know, could have been a lot worse. I learnt that from a very, very young age, to be grateful that I did have arms and hands.

Your parents I think gave you some very, very positive and strong foundations, didn't they with which to start off?

Absolutely. Yes, they did, yes.

Okay, so you've answered my questions about the Thalidomide Society there and we've talked about prosthetics. So education, primary school, not so good.

No. My mum and dad had to fight to get me into a mainstream school. I went to a local nursery, which was private, which my mum and dad paid for. A neighbour's child was going to this nursery and they asked, you know, "Would Sarah like to go as well?" So that was fine because it was paid for privately and then came the time to go to infant's school and the local authority wanted me to go to the local special needs school, Kennel Lane, which is still around and surviving today, and still going strong. But my mum and dad said, "No, there's nothing wrong with her brain, she's perfectly intelligent and she can write and she can read. We want her to go to a mainstream school." The local authority sent a doctor to assess me. Mum said it took about two hours for him to asses me to see if I was capable of going to mainstream school which in the end, yes I did. I went to Holly Spring Infants and Holly Spring Junior school.

How was that, school life for you?

Probably in the infant school … probably my memories aren't too good about that time but that was fairly good, a fairly happy infants school. I made a group of friends, I used to come home at lunch times for dinner and at five / six years old I was allowed to walk home by myself …

Wow!

… [laughs] because in those days, yes … unthinkable nowadays but yes, I used to go home for lunch. I used to enjoy painting and drawing and, yes, I saw myself as one of the other children, I didn't see any difference and I don't remember anything bad about my time in infant school.

Did you have to have any special help or support with anything?

No. None whatsoever, no.

Okay. So even using the bathroom and mealtimes, everything was all fine.

Yes. It was, yes. It was perfectly normal, straightforward, as was junior school when I moved from the infants up to the junior school. That started probably towards the end of junior school to get a little bit more upsetting with the bullying. The kids were older and they knew there was a difference with me. As I said, I was the only disabled child in the school. Not that I saw myself as disabled, because I didn't. I thought I was perfectly normal, my hands and arms could do exactly what everybody else's could. But I used to be called names and that was quite upsetting. But I did not run home to my mum to tell her that I'd been bullied and I did keep it to myself because I knew the weight of guilt that she carried and I did not want to add to that in any way, shape or form. So even as a very small child I kept those name callings and things to myself and I didn't discuss it with my mum or dad.

What was that like, keeping it to yourself? Did it feel difficult or did you just sort of shoulder that as a …?

I think I just shouldered it, yes, and got on with it. I think I was probably quite a strong little character and I basically just got on with it. Sometimes I'd give verbal abuse back and try to retaliate. Once there was a boy with glasses that had called me names so I started calling him four eyes and then one day I was walking past his house and his mum came out and said to me, "Don't call my son four eyes anymore!" And I looked at her and I can remember thinking, "But what about what he called me?" And she was very finger – wagging and, "Don't you dare call my son four eyes! I won't have that! I'll come up the school if you call him four eyes anymore!"

And I bet you didn't say anything to her, did you?

I did not, no.

Kids never do.

No. I just took off home … for home, yes. I think I did mention that one to my mum. I think I said to her, "Oh, that lady had a go at me, so-and-so's mother," I said, "Because I called her son four eyes" My mum probably said something like, "Well, that wasn't very nice, was it?"

I know and you still probably didn't say anything, did you [laughs]?

No. I didn’t, no [laughs]. I think real bullying started at senior school though.

Secondary school.

Absolutely, yes.

Had you by this point, before somewhere in between primary and secondary school, had you got compensation through from the Thalidomide Trust? Do you know …

I don’t remember, no …

... when that happened?

I don’t remember any of that. I don’t think my parents discussed that side of things with me. I was aware that my mum and dad were going to lots of meetings and meeting with solicitors and barristers and I once remember being taken to London and sitting in chambers in London with barristers and solicitors around me, asking me questions. And two doctors were there, one of whom I know was a Dr Drummond, because we lived at Drummond Close at that time so I remember that doctor’s name and I was given an assessment at Chailey Heritage. Yes I was assessed at Chailey and I do remember going to Chailey and that was my first experience of seeing people far worse than me. People had polio at that time and were in polio machines, that’s what I can remember of that time. But no, I don’t actually remember discussions about finances or whatever, no.

So your parent just sort of took the responsibility of that?

They did, yes.

Okay, so secondary school …

Yes.

That was the bad school experience?

Yes, it was. Absolutely. That deteriorated over years. I do remember the very first day of going to school, we were all led into the hall and everybody was being put into classes and I was left right until the very, very end and my name hadn’t been called and I was getting quite upset and the head teacher stood at the front and he said, “Sarah Higginson,” he said, “We’d like you to choose which class you would like to go in” so I picked the class that had a lot of the children that I’d gone to primary school with and that was the reason why I chose that class. But I did feel singled out and I probably wished that I'd been treated like everybody else and put into a class …

… from day one.

… from day one, instead of in that massive hall with all those children staring at me and me having to choose which class I wanted to go and sit with. I remember that very clearly.

Because it sets you apart, doesn't it?

Yes, it did. Yes, it did, yes.

What happened from then on?

I was treated normally at school by the staff, no different to anybody else, nothing special. No allowances for writing or homework or … I was just expected to keep up with everybody else and do what everybody else did. PE, treated no differently, I had to play hockey, had to play netball, had to play rounders.

Could you manage that?

I could, yes. Wasn't so good with the hockey stick, that probably wasn't my best sport. Rounders, I had a couple of accidents. I've got a bit of a bump on my nose where the rounders ball hit me twice in one game in the same place and yes, damaged my nose. So yes, that was fun and games.

Yes. You were probably better at sport than me. I was really rubbish.

[Laughs].

And what about other kids then? How did you fit in with them?

I had a small group of friends because I'd gone into that particular class where I knew people from primary school and we formed a cliquey little group which I stayed with through most of my time at secondary school. It was as we got towards year four and five; fourteen / fifteen that things really deteriorated with that specific group of girls that I was with. They sort turned against me. Boys were coming on the scene, boyfriends were turning up and obviously I wasn't getting a boyfriend, boys weren't interested in me. All boys did to me was call me a spastic.

Right.

That was the favourite name for me throughout senior school, was spastic. And I used to turn round and say to them, “But you don’t know the meaning of the word” because I thought, “I’m not a spastic.” And at that time there were no other disabled children in the school so that seemed a really good word for them to pick on and it was probably uttered every day, day in, day out, and I was the spastic at school.

The group of girls that I started off with were fairly good and did surround me and were friendly and I used to go to their houses and play with them after school and do various things with them. But as I said earlier, when we got to fourteen / fifteen, that’s when it all started to break up and they started to go off with boyfriends and I was then left on my own because boys didn’t want to go out with me and I found that time really, really difficult then because it set me apart from everybody else and all the girls that I’d been really friendly with.

I was sort of alienated in the class as well and it actually took the head of year quite a long time to work out that something was going on because I didn’t tell anybody that I was being alienated from this group and I used to sit on my own in class. And one day this head of year came up to me and she said, “Is everything all right Sarah?” She said, “I’ve noticed you sitting on your own.” And I said, “Well they don’t want to be with me anymore, they don’t want to be friends anymore.” And she said, “Do you want me to have a word?” And I sort of shrugged my shoulders but I think she did have a word and then of course the girls came back to me, “You’ve been blubbing about us to the teachers. We haven’t done anything to you, you’re just a horrible person and we don’t want to be friends anymore. Don’t go behind our back!” It was all that type of thing that went on.

So I didn’t bother saying anything to anybody any more about it but it did make me seek out new friends in other classes because the form class then was mixed to go to different lessons. In those different lessons I made friends with other girls and it was a really hard time for me and I did manufacture quite a lot of illnesses so I didn’t have to go to school. I had a lot of tummy troubles, a lot of tummy pains. My mum and dad I don’t think realised what the actual cause of it was but they took me to the doctors and to hospitals to have stomach assessments and things and the doctors said that I just had antacid stomach and they used to give me antacids. But it was this fear of going to school and these girls alienating me and me being on my own. Once or twice I was bullied physically, beaten up, punched in the face, hit over the head with a guitar on the way home from school. Obviously, Mum and Dad found out about that and went to the people’s houses responsible to their parents and said, “It mustn’t happen again” and it didn’t. There was only two occasions, I think, when I was physically beaten up.

It’s very painful to hear about, you know.

Yes. But the old saying, ‘What doesn’t kill you makes you stronger.’ And I can look back now, and then, in later years, my teenage years, to think that God works in mysterious ways. He knew I couldn’t be with those particular girls for the rest of my life and they wouldn’t shelter me and protect me and I feel that probably it was a way of me learning to cope on my own and to face different situations and to meet new people and for me to be able to make friends with other people, different people outside that close-knit circle that I’d had.

And I stayed on at school for an extra year. Some of those girls did stay but the majority of them left so then that was another time of having to make new friends with different people. Boys still weren’t interested, still. But I went out with various people to the cinema and local youth clubs and things and went after groups and things like other girls do, Bay City Rollers and The Osmonds and David Cassidy. So I had quite a full life. I went to concerts and things like that. And then I left senior school and went on to college.

What subjects were you particularly interested in or good at secondary school? Did you seem to lean anywhere?

English. Yes, I did. Definitely English.

Don’t blame you.

Hated Maths. I failed CSE Maths at the time but got a B at O-level in English so … and I liked Social Studies and History. Didn’t like Chemistry or Physics but loved Biology, absolutely loved … especially human Biology, really loved human Biology, yes.

What about things like Art? Did you still enjoy doing Art?

No, because I couldn’t draw [laughs].

Well that probably a bit against you, isn’t it, really [laughs]?

Yes, yes. I couldn’t draw to save my life.

And reading and things? Did you enjoy reading?

Oh, yes. Even today I am a bookworm. That is my passion, is books. Love reading books.

What sort of things do you like reading today?

Oh, today? Romance or whodunnits, murder mysteries. Anything I can get my hands on usually, yes.

It always feels for me, if I haven’t got a book on the go somewhere, something’s missing.

Yes, yes. That’s right, absolutely. Absolutely. I’m a horror about my books, I really am. My husband gets so fed up. Books in the bedroom, everywhere.

And what about medical interventions? You said that you were going up to Great Ormond Street until you were about sixteen?

That's right, yes. A little while after sixteen my mum and dad heard of an operation that was being carried out to turn a finger into a thumb and that was at a hospital in north London and they did ask to see the surgeon concerned and they also asked to see other children that had had the operation. I do remember going to this hospital … I can't think of the name of the hospital in north London we went to. And the surgeon said yes, he could turn my little finger and turn it into a thumb and turn it to the side … [SG demonstrates].

Oh, I see. So sort of on that side.

Yes. And turn it on that side and turn it into a thumb. But my mum said, "Well will it make her be able to do anything different?" "Well, you know, is it just for cosmetic reasons or will she physically be able to do more than she can do now?" and the doctor said basically it was for cosmetic reasons so my mum and dad decided that wasn't worth the operation, just for cosmetic reasons because my little fingers are the two fingers that have got the most flexibility and they are the two that I use the most. The other two, they're stiff, there are no joints in the other fingers at all. So thankfully they didn't agree to that operation.

Thank goodness they didn't. What a difference that could have made …

That's right. Absolutely.

… you know, for the wrong, actually.

Yes, yes. That's all I can remember.

Yes, in later years, in the last ten years I've had a carpal tunnel operation on my right arm. That was an interesting experience. Went to the local hospital … I'd been having nerve pains in my arm and lots of aching and lots of pains and numbness in my hand and they said, "Well, it sounds like carpal tunnel." So I actually went to the plastics team at Wexham Park Hospital in Slough and they performed the carpal tunnel operation. Usually you're awake for a carpal tunnel operation, they just numb your hand and arm and you're awake. But for me they decided it had to be a full operation and they put me out because they didn't know when they got inside the hand what they would find, where the main nerve was, and what they'd be able to do so they decided it would be best to put me out completely. But yes, the operation was a success and it did get rid of the pain that I was suffering at that time, though it's probably coming back again now but I'm not sure if I'll go back for another operation, yes.

Do you tend to find that when you go in for things like surgery like that, do you generate more interest from medical professionals around?

Absolutely, absolutely, yes. I was subjected to all the students … it's a teaching hospital anyway and the plastics team brought all the students round and said, "This is a carpal tunnel operation, it's slightly different from the norm." And, yes, all the students came round to have a look. So I did endure that. I had concerns myself and I did say to the surgeon, it was a lady surgeon, "Well you've obviously not done this type of operation before," I said, "How do you know what you're doing?" And she said, "Well, I've done many carpal tunnels before," she said, "It is a very straightforward operation," she said, "All I need to do," she said, "Is locate the nerve." And she said, "We've taken lots of x-rays and scans and things," she said, "I've got an idea of what I'm looking for and where I'm looking for it" she said. "I think it will be okay." So that had to be good enough that she thought it would be okay to go in and do this operation. But it was, it was fine. It was a success, yes.

And how do you feel when you do get that extra medical scrutiny? I mean do you get to a point in your life when you think, "Oh, not again" or do you not really mind?

I don't mind because I know this is so different from anything that medical students would have seen before and I suppose it's an education for them and I think, "Well, if I can help educate somebody else, then why not?"

Yes. That's very generous of you. So moving into the time of early adulthood.

Yes.

What were your … if you can remember, what were your feelings about your impairment as you were probably around that time when you were maybe starting college, you said? You mentioned no interest from boys and that kind of thing?

That's right, yes. Yes, I went to college. I did a secretarial course so the whole class was girls anyway and I got on really well with all of them in that class. That was actually quite a positive experience. It was a year's course, typing, shorthand, business studies and there were some really nice girls there and we all got on quite well. We used to go out a lot together as well. I used to go round their houses and have evenings out and we'd go to the pub and that sort of thing, because I was seventeen / eighteen then … go to the local nightclub. Yes, that was quite … after the senior school experience, the college experience was quite a positive one.

That must have been quite a relief for you.

It was. It was, and I think because people were approaching seventeen / eighteen / nineteen, it wasn't like little kids at school where they call you names and everybody treats you in an adult way, the teachers and so on, the staff at college treated me just like everybody else. I had to have an initial assessment to see that I'd be able to keep up with everybody with the shorthand, would I be able to type?

How did you manage to type?

I worked the keyboard that way [SG demonstrates]. Instead of up and down I worked from side to side. I touch typed …

I'm trying to imagine that. So same keyboard as normal …

Yes, yes, yes.

And these days they'd be the big clunky typewriters …

Absolutely, yes, the IBM. But I probably had an advantage because I'd started typing before I went to college. I had an electric typewriter at home which must have been provided by the Trust at some point. I don't quite know where the finance came from that but I did have an electric IBM typewriter at home so I'd started to teach myself typing at home. So when I got to college and I sat in front of the tutor and he said, "Well show me how you're going to type" and I started typing and he was quite surprised because though my speed wasn't great, I wasn't making too many mistakes and I was actually getting through letters and things and he was quite surprised. It was a male tutor for our typing lessons and he was a great teacher, he really was. I got on really well. Mr Perkins, his name was, and he was excellent. His wife actually, Mrs Perkins, she taught at the college as well and in later years I got to know her outside of college. I'm not quite sure how I got to know her but they were, they were a lovely, lovely couple and they did keep in touch as well, outside of college.

That's great. I'm so glad to hear you had a good experience there at college. And so that was for about a year?

Yes it was, yes.

And what happened after that?

Then it came time to leave, I got some qualifications, and had to find a job. And I set my sights quite high. I applied to the BBC and got an interview but didn't get offered a job. I was told by the lady there at the time that they probably didn't have anything they could offer me. Whether this was to do with the disability or what I'm not sure. Probably looking back now it probably did have more to do with the disability than them not having a position for me to fill because I got the same answer near enough everywhere else that I went.

I was a great football fan at the time. I used to go most weekends with my dad and my sister to Queen's Park Rangers in Shepherds Bush. So I applied to Queen's Park Rangers for a secretarial job; got an interview again. I remember taking all my girlfriends from college with me because I was driving as well. I had car at that time and none of them did. And I went for this interview and once again, "No, we don't feel that you'll be suitable for this position." And that happened at quite a few places. I did eventually get offered a job over at Slough for a German company, funnily enough, and it was an admin assistant's job but I only stayed there a couple of weeks and I didn't like it, I didn't like the office set-up. People weren't particularly friendly so after a couple of weeks I actually gave my notice in and left, came back to Bracknell.

My mum was really fed up by this time that people weren't giving me an opportunity to show what I could do before turning me down. Even application forms when I put down that I had a disability … the number of application forms that didn't even get answered, you know, it was incredible really. My mum at this time was working for a company called Sperry Gyroscope which later became British Aerospace and she worked on the assembly line and she said, "Well why don't you apply to Sperry's and see what they've got?" So I did, I filled in an application from that my mum had got me and it came back, "No, we don't have any vacancies at this time." But my mum didn't give up. She actually took the application form and went to the personnel department or human resources, as it's now called. And she said, "Look, my daughter has got a disability, she's put this on the form. She's a very good typist, she can do shorthand, she's a very intelligent young lady. Why don't you take her on with no pay and give her a chance, an opportunity for her to show you what she can do?"

I like your mum.

And she actually … she got to speak to the director of personnel at that time and he said, "Okay then, there is a position in our accounts department. They need an admin assistant to help the secretary to the chief accountant." So they took me on. I don't think I got any pay for the first few weeks but after that I was taken on full time and with pay because they could see I could do everything they threw at me and it was a really good team and I ended up staying there eleven years.

Wow, that's brilliant.

And I actually moved up from admin assistant to the secretary of the financial accountant and became the secretary to the chief financial accountant.

Fantastic. And all because your mum opened that door for you.

Absolutely, yes. Just said, "Give her a chance" And I remember the personnel director coming to me one day and I was actually doing some work in the foyer at the time, of the building I worked in and he said, "You are a remarkable young lady," he said, "And you are a credit to our company," he said, "Keep up the good work." I remember that.

That's fantastic. So in a way I suppose you could say until that point you'd encountered some disability prejudice, hadn't you?

Absolutely. One hundred percent, yes. Especially back in those days, 1979, late '70s, early '80s, yes. Most definitely.

And whilst you were doing that job though, in those eleven years, did you still come across any prejudice from other workers or people you had to come across?

Not really it was quite a happy time there. Got on with everybody in the department. It was a very large accounts department. We'd have staff come over from America because Sperry Gyroscope was an American company and no, everybody was lovely because it's an adult environment. It was totally different from me being at school with the children and the spastic comments and that. No, my eleven years British Aerospace were good years, yes. Lots of happy times.

One thing I wanted to ask you about. So all of this period of time from secondary school up until now, as well, did you talk openly about your disability ever? I mean, do people ask you and say, "Were you born like this?" Or did people realise you were affected by thalidomide or was it something that didn't really enter into …?

Not a lot, no. I think the comments have mostly come from children. "Why are your arms like that?" when you're walking through the supermarket and your in the company of children, even nowadays. Last Saturday I had two little boys following me around Tesco's and they were quite curious but … Yes, I think people did talk about it. It wasn't a secret and if people asked me I always responded and answered and said why, what and how but I can't remember any nastiness attached to it or … just curiosity really.

Yes. I was wondering … I was thinking more of sort of close girlfriends you know, when you sit down and you have heart to hearts about things, if it ever came up as a subject where you talked about your disability specifically or if that was just in the background of the person that you were?

No. I think the nicest comment I ever received from a girlfriend was … we were talking about disabilities and somebody said, "Oh, yes. Sarah's disability" and this lady looked round, she said, "Sarah's disability?" And she said, "Honestly, I don't look at you and see disability," she said, "I see you as the whole person." And I think that was the greatest compliment I've ever received. And I take that as a sure sign of friendship when people don't see the disability, they just see the whole person.

Yes. I think that comes a lot with experience, as well. I think when something's very new to people sometimes they react badly whereas I think now in schools, because disabled children are integrated so much more strongly, I don't think children have quite such a knee-jerk reaction against them as they used to.

Yes, yes. I would hope not. I mean. I've been out of school a long, long time but I would hope not, yes.

Were you still living at home whilst you were working for British Aerospace?

Yes, I was. Yes. I didn't leave home until I met my husband and that wasn't until I was twenty-six.

And were you,, at this point in your life, … so at this moment you were at British Aerospace, how old would you have been then?

Eighteen. I started when I was eighteen at British Aerospace and worked for the next eleven years.

Okay. So until you were twenty-nine.

Yes.

Did you still have any contact with the Thalidomide Society events or other thalidomiders?

Yes. All the time, yes. Yes, I used to go to all the meetings with Mum and Dad. We used to go every year, yes.

And did you go to any of the Thalidomide Trust organised holidays, those holidays abroad?

I used to go to Hague Moor in Jersey, yes. I went with my parents quite a few times and then later on when I hit seventeen / eighteen I would go … I went with my cousin Denise and she would come with me. I didn't go on my own ever but I don't remember going on any other Trust holidays apart from Hague Moor.

What was it like? Have you got any recollections of Hague Moor?

Yes [laughs].

Was it a bit wild [laughs]?

It was a bit wild, yes. Lots of drinking and nightclubbing and I'm sure sexual experiences went on but not that I was a part of that but still I didn't get involved in that but yes, all that went on there.

Yes, I've heard some crazy stories.

Yes. It was a good place though, right on the sea front there and a little swimming pool out the back. Yes, we had some nice holidays in Jersey, yes.

And how did it feel having peer support from other thalidomiders at that time? Was that still something that felt quite a relief to be amongst other people with similar …?

To meet up every now and then, yes, yes. Familiar faces and so on. I also found that even in the thalidomide group it could be a bit cliquey so I found that the Liverpool lot would stick together and the London lot would stick together, they didn't seem to branch out of their little groups and mix with other people, so yes.

Okay. So at twenty-nine … your financial support from the Thalidomide Trust at this point, was it something that you had control over or did your parents take control of that?

I know the Trust was set up in 1973 and I would have been thirteen. I don't remember anything then about that except that my dad got a new vehicle. He got a VW Volkswagen, it was orange and white, and he told me he'd got it through help from the Trust in order to run me around and be able to take me places and things that he'd been allowed to have a vehicle. Then when I turned seventeen the Trust paid for me to have driving lessons and I passed my test first time and they bought my cars. I had a red Ford Escort to start with. That's what I actually passed my test in as well because it had been adapted for me and I knew then that the Trust had paid for that, they'd paid for the driving lessons. When I was eighteen, I got a cheque through and Mum and Dad said that was the compensation that had been held by the courts for me and I was then, at eighteen, allowed to put that into my own bank account so put that into a savings account. I did draw on it and I did use it but the bulk of it remained there and I didn't really touch the bulk of it at that time because I was working as well and getting a salary. And actually that money came in handy when I got married and started this home up because that money then paid for furniture and so on in this home.

Yes. Okay. So what happened to you work-wise after age twenty-nine?

Actually, British Aerospace shut down so everybody was made redundant. It was like a staggered redundancy, I left before my mum. I then had to apply for other jobs and very, very fortunately a job became available at Frimley Park Hospital in the occupational therapy department, secretary to the head occupational therapist. And I thought, "That sounds interesting" and it was a part-time job so I was going from full-time to part-time but I'd been married for several years at this point and I was hoping to start a family. I was having trouble conceiving, I was actually trying for four years before my first son come along so I thought, "Well part-time work is probably good to go for as I'm trying to have a family as well" and I got the job. Had the interview and got the job straight away.

What a different experience to previously.

Absolutely. But I think going into the culture of the medical profession, going into an occupational therapy department, made all the difference.

But also you would have had all those years of a good track record behind you as well.

Yes. Exactly, yes.

And how long did you do that job?

I did that for two years, I think, before I fell pregnant with Dale. Then I went back part time after I'd had Dale but that did get to be too much then and travelling backwards and forwards from here to Camberley, where the hospital was, and having Dale and juggling the home, that then … I started to realise, "It's all too much" you know, handling this child. So I then got a job in Bracknell. That was again first interview, first job and that was at a centre called Margaret Wells Furby which was an assessment centre for children with special needs and it was owned by NCH so I got that job. That was part-time, less hours than I'd been working at the hospital and my mum looked after Dale and I think I was only there for a year or so and I fell pregnant then with Aidan. And then really, I continued working up until six weeks before I was due to give birth and then once I'd had Aidan, and all his problems, it was then far too much to go back to work so I haven't worked since, not in a paid job. Voluntary I've worked but not in a paid job since I had Aidan seventeen years ago.

We need to add in to this story about meeting your husband, don't we?

We do, we do.

Was he your first boyfriend?

Yes, he was, yes. Funny enough there's a story attached to that. I worked at British Aerospace and I worked alongside another secretary called Gloria and we used to go on skiing holidays together which were organised through British Aerospace; they had a travel club and several other people in the department and their families used to go on these skiing holidays to Austria. This had been going on for a quite a few years and then one year, Gloria said, "Oh, I think my brother might like to come on a skiing holiday." I said, "Well funny enough, I think my mum and my dad and my sisters want to come this year as well."

Yes, turn it into a big affair.

Yes. So it was back to Austria. We went to Soll and Gloria's brother came on this holiday and we got very friendly on this … I think it was about ten days or so. And he liked me and I liked him and when we came back he said, "Would you like to meet up?" and I said, "Yes, I would."

How romantic.

Yes. So we actually got together on this skiing holiday and then continued when we came home and we were married just over a year later.

So it was one of those, just gelled together and …

Yes, yes. And funnily enough, when we were discussing getting married, I tried to put Trevor off and I said to him, "You know I can't do certain things and you'll probably have to do more for me than any other husband." And he said, "I know, that's all right, I still want to get married." And his parents were excellent. They have never, ever said anything about Trevor marrying me, not to him, not to me. But he had one uncle, it was his father's brother-in-law and he actually said to Trevor, "Do you know what you're taking on here?" and he said, "Is Sarah going to need lots of adaptions in the home, have you thought about this?" And Trevor said, "Well actually she doesn't need a lot of adaptions," he said, "She's got a special toilet," he said, "But we're having that fitted in," he said, "But other than that she doesn't need anything else" and left it at that. But that was the only person that ever said anything to him about him marrying me. Because I'd known his family a lot longer than I'd known him.

Through your friend.

Yes. Because I'd worked together with her for near enough eight years. I knew all about the family, I knew all their ins and outs, their secrets and things that they didn't know between themselves and actually that friendship, once we'd got married, that friendship between me and Gloria then actually suffered.

Oh, did it?

It did, yes.

I was hoping you weren't going to say that.

Yes, it did. Absolutely. Because she'd told me so many things about the family, skeletons in the closets and so on that did start to slide, that friendship.

Yes. Did you get it back again?

No, never. No, in fact we don't have a very good relationship with Trevor's sister and her husband. We have a semi-good relationship with his other sister, we don't see her that often, but have a good relationship with his mother, his father's now passed away. We have a good relationship with his mother.

What about your sisters, are you still in touch with them?

Yes. There's another story. My middle sister, which is the one that's two years younger than me, she's very resentful of me, extremely resentful of me and my life. She's got problems, she's had behaviour problems since she was a child and I'm convinced she is somewhere in the autistic spectrum. She lost her job three years ago and she actually blames me for losing her job. She had a major back operation and she couldn't … she worked for the post office … she couldn't lift heavy post bags any more so her duties were getting more and more reduced and it got to the point where the post office really didn't want to employ her anymore. She'd been with them twenty two years and she asked me to go with her to see their doctor and I did and I supported her and it just came about that they wanted her to go back out on a delivery again and she couldn't do that and I said to her, "Louise you really can't do this, this is going to make your back even worse, it puts you in a terrible position." I said, "They're offering you redundancy, it will probably be a good idea to take it" and that's what I said to her. But since that time, three years ago, three or four years ago now, she's not been able to get another job and she has held that against me that I gave her advice to leave the post office and our relationship now is at nil. We don't speak and I don't see her. She still lives with my mother as does my younger sister. Louise did get married and leave home for a short while but her husband had an affair so that marriage broke up and Louise moved back with my mother. My father died, oh nearly twenty years ago now, he had Alzheimer's, and he had diabetes and he'd had strokes.

Oh dear. So how come your younger sister still lives with your mum as well?

My youngest sister, she has never left home. She has really been my mum's support and carer. She supported my mother through my father's illness and she's still there. She doesn't really have a life of her own. She's a mobile hairdresser but it's not a thriving business and she does elderly ladies' hair as and when they phone her. But no, she doesn't really have much of a life which I find quite distressing.

Well it's a shame isn't it?

It is a shame.

How old would she be now?

She is eight years younger than me so she's forty-two or something.

Forty-two or something like that.

Forty-two. Yes, that's right.

Right. Because you didn't mention your sisters much when you were talking about your childhood or what your relationship was like with them when you were younger.

I have a good relationship with my youngest sister, Frances. She comes round and she'll cut my hair and she cuts my children's hair and my husband's hair and she pops round every now and then. So I have a good speaking, close relationship with her but the relationship with my other sister is very prickly. It's at the moment, non-existent.

Do you think it was like that when you were kids or were you closer as children?

No it wasn't, no. We were closer as children but Louise always had behaviour problems. She was very reserved as a child, she didn't speak. Also I think it affected her, mum and dad having to take me to so many different places and doctors and hospitals, and Louise was left with relatives at the time, so … but we were close as children, we always played together, give us a cardboard box, we'd make a camp and we always played together but she was always very reserved as a child. Her communication skills and social skills weren't as outgoing as I was. I was the one that always had lots of friends around where we lived. She tagged along, she didn't have many friends at school whereas I probably had quite a big group of friends, used to go out quite a lot until the end of senior school and that all died off. But Louise never really had a big circle of friends. I don't remember her going out to youth clubs and things like that and I do believe she's got social interaction problems, definitely.

Well they do say that autism can pass through families, don't they?

Yes, absolutely. Yes, that’s right.

And it doesn’t often get diagnosed in girls in the same way because they don’t always have the language delays, do they?

No, it doesn’t, no. Exactly. My mum did try, she did try to get Louise diagnosed but you’re going back to the ‘60s and ‘70s and mum took her to Roehampton, she was offered a psychologist to see at Roehampton and she dragged Louise there kicking and screaming all the way there and all the way home and that petered out and didn’t ever resolve itself. But no, Louise has always been a difficult child. Going from a reserved child to a very argumentative and violent child later on as she grew up. But Francis is more like me, she’s more placid, Francis, my youngest sister and we’ve always had a good relationship. She would do my hair at home, brush it … I think that’s probably what got her into hairdressing but she would help me wash my hair, she would blow dry it for me and style it for me, even when she was quite young she used to like doing that. And that then led her … she went off to Reading College and did a hairdressing course. But she’s never moved away from home, Frances, and I think I do feel so sorry for her that … she needs a life, yes, she needs a life.

And what about you? When you were married did you come straight to this house where we are now?

Yes. We had this house in the May and we got married in the September of ‘87.

It’s a lovely house. Very lovely. I love these shapes in here, with the archway.

Yes.

So this was your first married home?

Yes, it was. Yes.

Yes. And you mentioned that it took you a little while to conceive but that having children was very important.

Absolutely, yes. I always wanted to have children. Yes, it took me over four years to conceive Dale and we were on the verge of getting tests and things done. Trevor had had a test and he was fine and I were just about to go to the hospital for me to have scans and tests when I found out that I was pregnant so they were all cancelled but it did take four years. But then Aidan came along, you know, we said we’d have a second baby and he was there [laughs].

Yes. And how did you feel when you first got pregnant? Was it something you felt, you know … did you have any anxieties about it due to your impairment?

Yes, I did. Yes I did, yes. I wondered how I was going to cope and manage. I'm quite a determined lady so I knew I would. It's just the practicalities of things of how I would do certain things. We had the bedroom upstairs, a sink put in, and it had a changing mat and table by the side of it and Trevor, my husband, made it … he's quite good with his hands, and it was all at the right height for me to be able to bath the baby in the sink and put straight onto the side for drying and changing and that, which made life a lot easier. Because to bend over the bath and bath the baby we thought would probably be too hard on my back and it would have been.

Absolutely. It's hard to lift a baby out when they're wet as well and they're all slippery aren't they?

Absolutely, yes. So it went straight from the sink onto the side and it was … yes so Trevor built all that and did all that for me. So we did think about it and plan before the baby arrived, of what we would need, yes.

And how did he feel about becoming a father? Was it something he really wanted as well?

Yes, absolutely. Yes, definitely. And he did a lot in the early days, of the bathing and the feeding and the … I couldn't breast feed, that didn't work out. Whether or not I wasn't able to hold Dale in the right position or what but it just got a very painful and unhappy experience so we stopped and went on to bottles and I used bottles straight away with the second baby.

Did anybody ever make any unkind remarks about you having a baby, being a disabled woman, or express any doubts in you?

No. Not to me personally, no. Nobody ever said anything to me personally. With the second child, because of his behaviour, with the autism and the behaviour tantrums out in the supermarket I myself placed burdens on me by thinking that people would think it was because I was a disabled mother that this child was misbehaving and screaming and throwing a tantrum in a supermarket. I was always very, very conscious of Aidan's behaviour outside the home being a reflection on me but I never, ever felt that with the first child because he didn't have the same problems.

In fact my first child, Dale, was probably far more mature for his years realising he had a mother that was different and even from a tiny baby, he would hold on to me, he would hold my clothes or my chest when I was holding him. And I don't know what this was, this bond with this child but he knew from a very early age that his mother was different.

That's interesting.

And he would help me, a two year old helping fold the sheets up, he would hold them and help me fold the sheets up at two years old and he would help me with cooking and it would be, "Me do it mummy, me do it mummy!" And he knew, he was wise beyond his years.

Sounds lovely.

He really was, yes. He really was. A very loving child, very loving. Very protective. Both the boys are. Even with Aidan's learning difficulties and his autism, he is very protective of me as well. Like this incident in the supermarket of the little children following me around and looking, he will stand there and Aidan will stare at them and if they go to go around him to look he will move. He won't say anything because he hasn't got the verbal ability to make a comment but … very, very protective of me, both boys are, very protective.

Can you tell us, for the interview, a little bit about Aidan, when you first realised he was suffering with, well, not suffering with … he was born autistic?

Yes. Well from when he was born we knew he had trouble with is stomach, with allergies because he kept bringing milk up and he was a very sickly child. Allergic to cow's milk, we had to put him onto soya milk. And then he started on solids and we realised there were allergies involved. He had a rash all over his skin. That really started it all off, going backwards and forwards to the doctor's. And then the health visitor picked up that language wasn't progressing as it should. No words, ten words, if that, when he was two / three years old. And she asked me if I wanted to go to the Margaret Wells Centre where I'd worked and I said, "Well yes, I would." I do know Margaret Wells Centre very well and yes, it would be a good place to take Aidan to get a paediatrician's work there and physios and OTs and Aidan could have a proper assessment to assess the language and the behaviour and no eye contact. So that started …

Did you have suspicions yourself?

Yes, I did. Yes, definitely. We knew things weren't right. Then we had a big breakthrough actually, just after that. We had a lot of tests run on Aidan to see what he was allergic to and yeast and sugar came back as a big problem and Aidan used to steal sugar. He would climb up onto the work surfaces, get into the cupboard at two years old and steal sugar out of the sugar basin or the sugar packet and he would he would shovel it in.

How strange.

So we got rid of all the sugar in the house, we just threw it out. We stopped having sugar in our teas, coffees and everything and got rid of it. He was given some medication by a very good doctor called Dr. [Tettenbourne?24:22] who was a paediatrician at Frimley Park who we'd been referred to who was dealing then with children with autism and diets, that was his speciality. And we had this medication. Within ten days of Aidan not having any sugar and having this medication, Diflucan, which was a yeast … like candida of the stomach that got rid of the yeast and the candida that was going on inside Aidan. Aidan started to speak, fifty words appeared within ten days, it was amazing. But he went through symptoms right at the beginning like a junky. Streaming eyes, streaming nose, foul behaviour. Actually for a few days he was the child from hell and we didn't really realise that it was withdrawal symptoms from this sugar and from the die-off of the candida in his stomach. And then these words started coming and this conversation started and his behaviour gradually got better and better. So that was the big turning point, was actually to get his diet all in order, get his stomach sorted out and all that sorted out, but that actually continued up until he was about fourteen / fifteen. We actually got a referral to the Royal Free Hospital at the time of all the measles and mumps and rubella debacle, with Dr … I can't think of his name now, he got struck off for saying that measles was responsible for autism in children. We actually got to see this doctor.

Was that the doctor who said it was the vaccine against it …?

Yes, it was. Yes.

Was it? I know who it is … I'm thinking of Meadows but I think it was Meadows that was involved with the cot deaths things, wasn't it? I know who you mean, anyway.

Yes. It was that doctor who we got to see and his side-kick, Doctor [Merch?26:41] and Aidan was under them at the Royal Free for a good few years. But regardless of whether this doctor was right or wrong about the vaccine, Aidan did deteriorate after he had the MMR, the first one. He did deteriorate again. I never, ever let him have the booster for that. We didn't have the booster and I stopped him having the other childhood immunisations as well. But since his immune system has got stronger he has since had injections and things and boosters and we've not seen any adverse effects. But when he was in that really difficult period of when he was two, three, four, five years old … yes, I think the vaccine did do something to him and I do have a lot of sympathy for the doctor that, you know, was struck off.

It's a funny balance because it's a possibility but then a lot of people arguing against him say that those years would be the years that autistic children would get worse anyway. So it's just an unfortunate co-incidence that the age at which children have the MMR is also the age at which autism can sometimes show for the first time so it's quite hard to sort one from the other, isn't it?

Absolutely, it is. It is, yes. It is.

And there's also a big worry that measles will start coming back into the community and it's terribly dangerous, so I don't … it took me a long time to work out whether I was going to give my daughter the vaccine, a very long time. I did in the end but not until she was about three and a half.

That's right, yes.

I spent a long time deciding.

My eldest son had all the vaccinations and it didn't affect him but because Aidan's immune system was compromised anyway and we had to get rid of all the things that were wrong with him and get … and we did see him go from strength to strength. Once we'd implemented all these protocols with the dairy-free diet, the wheat-free diet and getting rid of the candida and getting his stomach in a much better, healthier position, he did go from strength to strength and he hasn't ever gone back, he's always made really good progress, year on year, to the really lovely young man that he is now.

That's fantastic. That's very good. I've got a few questions left to go ... are you okay to keep going for a bit? Yes.

A couple of things just flipping back that I've realised I didn't ask you about, some small things. One is, when you were at Roehampton, did you ever encounter a Sister Mears? A lot of people talk about a sister that was called Sister Mears.

Yes I think I do recognise that name, yes.

A sort of old-school, sort of nursing sister …

Yes. Yes, I think so.

Everybody sort of raves about her and apparently she was wonderful with parents as well but I don't know if you have any …

Yes, yes. A grey haired lady, yes. I think I do remember her.

And did you meet Lady Hoare?

Yes, I did. She used to come to my mum and dad's house for meetings with them quite often to see how they were getting on and to see how I was getting on. She always came with a Brigadier, I can't remember his surname and the Brigadier and I used to go off to the woods at the back of our house and pick bluebells while Lady Hoare used to speak to my mum and dad and we used to bring all these bunches of bluebells back to the house.

And what did you think of her? Can you remember what you thought of her?

It's a long time ago.

Yes, I know it's a long time ago.

Very well-spoken lady, always nice though, always friendly, smiling, yes, just a nice lady, interested in me, always spoke to me.

Okay. And what about religion? When you were brought up in your family home, were you church goers?

Well, my mum wasn't and never has been but my dad used to like going to church and he used to take me and my sister Louise to church on a Sunday quite regularly. We used to go to Warfield Church, Church of England, and I do remember that. My dad then changed his job and he got a shift work job which meant he wasn't around on some Sundays and then we stopped going because of that job. My mum never took us and she has a really hard time believing in God, you know, “If there is a God why am I going through this? Why are you like you are? If there is a God?” That’s her version.

And what about now?

And now, for the last eleven years I’ve been going regularly to Kerith Community Church which is an Evangelical church, it’s not Methodist or C of E or Catholic, it’s an Evangelical church, yes.

And does Trevor go as well or is it just you?

No. Trevor does not believe at all. I take the boys, Dale used to go as well but Dale no longer goes, he’s dropped off going but Aidan goes with me, he loves going because he’s really grown up in that church. He was part of the kid’s programme. Also the church has a very, very good track record with disabilities. It has a Friday morning mum’s support group for children with disabilities which I now run. It runs a respite club on a Saturday and during the holidays for children with disabilities which I’m also involved with. Aidan has gone to that respite club. It runs a hilltop club on a Sunday evening for adults with learning disabilities. It runs a deaf community club and we have signing on a Sunday. We have a big deaf community. It’s major in disabilities in our community, absolutely. In fact, our Bracknell Social Services could not survive without Kerith Community Church and they do recognise that because we provide so many services to the local community. We run a food bank, we run a debt agency, CAP – Christians Against Poverty. So the church is very involved in our local community.

And what made you go back to church? How many years did you say you’ve been going?

Eleven. It was when Aidan was a baby. I heard that one evening they were running a seminar on the whole allergy and autism thing so I thought, “Right.” I’d heard from a friend that was going on and I thought I’d go along and see what this is about and I met up with other parents of disabled children that were going through the same thing as me. So I started really on the connection side, which is the disabled families group and then I started to go on a Sunday. And then I realised they had a buddy system in place in the children’s work where I could take Aidan and Dale and Aidan would be looked after by a one to one buddy, an adult, because obviously Aidan’s behaviour at that time was quite severe. And I could go to church and take the children and Aidan would be safe in that environment and he could take part in the children’s work and it’s really developed from there.

That’s fantastic. It’s great that you’ve sort of found and added to that in your community, isn’t it?

Yes, definitely.

Okay. How about … we’ve talked about on-going health concerns because you said that you had your operation for carpal tunnel but are there any other problems, any aches and pains that have got worse as you’ve got older?

Yes. The same as all the others.

So shoulders …

Shoulders, neck. I've got permanently dislocating shoulders. I've got spondylitis in the neck, lower back, hips, knees, all the joints and bones are going and creaking and aching. If I do housework, I can only do sort of one thing a day then I've got to … I can't do nothing for the rest of the day because my back has seized up and won't allow me to bend and move. So if I clean here, that's it for the day. Once I've hovered, I can't do any other housework or anything else. I usually have to go and lie down for two hours.

Because it's so painful.

Because it's so painful and I'm so stiff I can't move.

Do you take pain relief?

No, because I am not very good at taking tablets of any kind or description [laughs]. I will only take Paracetamol if it's absolutely desperate. So I hope I never ever get a serious illness because I hate taking pills. I know that every pill we take has got a side effect to it, whether it's Paracetamol, Aspirin, they've all got side effects.

I'm exactly the same as you. I get an occasional migraine and it's such an awful headache that if I don't take something I just can't cope and then I take a tablet. But no, I'm exactly the same. Okay.

I normally like to rest. To deal with my pain I'll normally go and rest. I'll lie on the bed and rest for a couple of hours.

Have you tried any kind of massage or osteopathy?

Yes, I've been to the … we've got a chiropractic clinic just down the road here which is very good and they've put me on the tens machine and I've had the chiropractor cracking me around and all that sort of thing.

Did it help?

It did help but it gets expensive, too expensive to keep up on a regular basis.

It's about fifty pounds a session, isn't it?

Absolutely, yes.

What about your feelings about your impairment and thalidomide, how they've changed over the years? I'm thinking particularly about what you've learned through time about the origins of the drug and the responsibility of Grünenthal and those kinds of things.

Yes, well obviously I've learned quite a lot by going through to the Trust meetings, Martin Johnson has really enlightened us to the origins of thalidomide and Grünenthal's culpability in that and my anger … and they are fully, totally one hundred percent responsible and they are not owning up to this and dealing with it. It's just reprehensible, it's beyond belief, absolutely.

Yes. What do you think about that sort of 'apology' that they published?

Complete and utter rubbish. What a waste of time, just had no meaning behind it whatsoever. Fifty years too late. What's it done for us? What will it do for us? Nothing, absolutely nothing at all.

No. What would you say to them if you could in some way summarise the effect that thalidomide has had on your life or your family's life? How would you express that to them?

Well, I think it destroyed a lot … my mum and dad's life. My dad was never the same. He had a nervous breakdown, my dad, when I was a child and we had to move back to London to live with my mum's family because my dad was going through all the court case and everything and he wasn't an educated man. He'd left school at fourteen and he was suddenly being thrust into a world of solicitors and barristers, having to write letters and that wasn't something he was used to dealing with and it was a great stress and strain on him and I think his mental health suffered dreadfully, as it did with my mum in a different way. As I mentioned before, the whole guilt issue. She's a very angry lady, she's a very bitter lady that this experience did change her life and did change my dad's life. I think he died … he died twenty one years ago now, just after Dale was born. He had Alzheimer's, he had diabetes, he had strokes and he was only in his sixties and I think that was far too early for him to have died. But I think all the stress and strain over the years took their toll on him, they really did.

Maybe my mum was a bit stronger because obviously she's nearly eighty and she's still with us. But her whole character changed. She was a different woman after I was born. She says herself she was quite a reserved young lady before I was born. She wouldn't say boo to a goose. But once I was born and she had to start speaking up for me and visiting doctors and hospitals and so on, she then had to become a determined lady to get the best for her child. Probably that was one good aspect she passed on to me and enabled me to fight for Aidan and to stand up for his rights and so on. But yes, it did take an enormous toll on both of them.

For me, I feel it changed the course of my life. I feel … I feel I should have been a nurse, I wanted to be a nurse. I loved human biology. I have a great empathy for people. Whether that has come out of disability or whether that was part of my character anyway I'm not sure. But I feel I should have been a nurse and when I was at school when you were asked what you wanted to do, I always said I wanted to be a nurse and it was my dad that said to me, "Well, I don't think that's going to be possible, love, I think we need to look at secretarial work and typing and that." And I always feel that's something I've missed out on, not being able to do what I feel in my heart I probably would have done.

I could see you being a nurse actually.

Without a shadow of a doubt.

Yes, I could see it.

I really feel that that's … so from that point of view I'm sad that I never got to do what I was destined to do. I know that sounds dramatic.

No, it doesn't. It sounds perfectly reasonable.

I feel, yes … and I feel sad that when I step out of my house I stand out in the community around me. I can't be invisible. I can't go anywhere and be invisible and be one of the mass. I always stand out wherever I go, in whichever situation and I thought I would actually like to be a person who can disappear and be an observer of life and not be the person that's at the centre of everybody else's focus. So yes …

Yes. That's a very interesting way of saying it actually, yes. When do you think you started to realise that? Because I remember you said earlier on … I think it was mostly when you were at primary school, you never thought of yourself as a disabled person at all …

No, no.

Do you think there was a moment in your life when you suddenly did think of yourself in that way?

Yes, but that was much, much later on in life when I was an adult and it's probably been more since I had the children and I've got older and my body has deteriorated and I can do less and less for myself. So it's probably been within the last ten / fifteen years that I've had to face the fact that I am a disabled person probably because I am not as independent as I was as a child.

I see, yes.

And I think, yes, it's probably gradually over the last ten or fifteen years as my whole body has deteriorated greatly that I am now a disabled person.

Okay.

I actually heard a very interesting thing at the Paralympics. The lady, the swimmer, I can't think of her name, the little lady …

I know who you mean, yes.

I'm terrible with names.

I'm really bad.

She was on a news interview a few weeks ago and she was teaching awareness to normal children in a mainstream school about disability and she actually said to the interviewer, "I might be little but I'm not disabled" and I thought then, "Yes, I know what you mean but the rest of the world sees us as disabled." And I thought that was a really funny comment for her to make because she's only young, she's a teenager, isn't she? She's still at school or whatever. And I think I probably would have said exactly the same as her at that age and I did say it. "I'm not disabled. Who's disabled? I can do everything for myself, I'm not disabled."

Would you say that's something that … I mean this is just a possibility, is it something that separates thalidomiders from maybe other disabled groups, like people suffering from cerebral palsy?

Yes because thalidomiders never wanted to be disabled. In fact, there was a comment made to me … it wasn't made specifically to me, it was made in a group by a lady at church, lots of years ago. "Oh, disabled people get on my nerves, they're always whinging and whining and …" and I said, "No, that's not true of a really disabled person because they will fight against it and they will tell you they are not disabled." I said, "You come and meet the group of thalidomiders that I know and not one of them will tell you that they are disabled," I said, "Because we don't whinge and whine because we're too busy proving to the world that we can cope and we can battle and we can fight." I think that's been throughout most of the people like that.

I think so too. And why do you think that is thalidomiders in particular and not other disabled groups?

I don't know. That's a very interesting question. I really don't know. Because of the nature of our disabilities probably – limbs affected. I know there is ears as well but that's not so noticeable.

Ears and eyes.

Ears and eyes. It's not so noticeable as the limbs being twisted or whatever. I think maybe the nature of the disability. The fact that you've got to prove to the world that you aren't disabled.

It's interesting.

It is.

Okay, so we're up to the current day. And what's your favourite way of spending your free time these days? What do you really like to do?

I like travelling. We go on lots of nice holidays. We got into cruising recently. Well, not recently, the last three years. We've been on a cruise every year. My husband's not so keen. Of the four of us he's not so keen. But the three of us, myself and my boys, really love cruising and it is a really brilliant way to see the rest of the world and for me it's an easier way to see the world than having to book individual places to visit and use a car or a coach to get to different places to see lots of different places on one holiday. That would be tiring for me. It would be really too tiring and the packing up of the luggage and carrying luggage here, there and everywhere. From a practical point of view, a cruise is ideal because everything is in one place. You unpack once. People meet you at the airport, take your bags from you and it's just five star luxury.

I get to use the spa whenever I want, the swimming pool's there, you're waited on hand and foot. I don't have to worry about meals or cooking or providing food for the family, it's all on a plate in front of you. So from my point of view it is a very, very expensive but ideal way for me to see the world and I love seeing different countries and different cultures. I really enjoy that, I get a really big kick out of that. So, yes, the travelling, the cruising. And reading.

I was going to say, you like your reading.

I like my reading, yes. I like going out for meals with my family. I like going to the theatre, I like seeing shows, musicals and things like that I enjoy. I like being with my family, being with my sons. Just us all being here together watching the telly is good.

It's nice when everyone's together, isn't it? And what about hopes and wishes for the future? Is there anything you've got coming up that you feel is particularly important or that you would like to happen?

That would probably revolve around Aidan because obviously he's approaching the end of his school life and it's what comes next for him. But for my own personal self, I just hope I can remain healthy to be there for him, that I can remain alive as long as possible to get him further along in his life because I don't know how he's going to cope if something happens to me or my husband and the responsibility will probably fall on Dale's shoulders.

But yes, for me, it's to remain healthy for as long as possible to be able to keep looking after my family and for us all to remain happy and healthy, you know.

Yes, keep as strong for as long as possible.

As long as possible, yes. Definitely.

Is there anything you think we haven't talked about that you would have liked to have talked about? I mean obviously we'll do a follow up so if I kind of think, "I didn't ask her about that," or you think, "I should have said more," we can cover that. But is there anything immediately now that you think, "Why didn't we discuss that?"

I can't think of anything at the moment. Maybe if I have a little bit of time …

Shall we have a bit of lunch and a quick break?

Yes.

Thanks ever so much for that, Sarah.

END OF RECORDING