

# Thalidomide: Mikey Argy (2012)

Ruth Blue interviews Mikey Argy for the *Thalidomide: An Oral History* project.

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*Ruth Blue interviewing Mikey Argy on the 25 September 2012 at her home in Forest Row for Thalidomide: An Oral History.*

*Mikey, have you seen the copyright and consent form and are you happy with that?*

Yes.

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

Okay. My full name is Michaelina Argy ...

*I wondered what it was short for.*

And ... what was the next question?

*Date and place of birth.*

Date of birth is the 26th August 1962 and I was born in Melbourne, Australia.

*The first few questions are going to be about your childhood and birth, family and school life and early medical interventions. To start off can you just tell me a little bit about your family background, who your parents were, what kind of work they did, if you had any brothers and sisters.*

Okay. My mum and dad, my dad is an actor, was an actor, but once he started having children he became an Encyclopaedia Britannica salesman. I think that's what he was doing when I was born and my mother was, you know, she had two children before me, an older brother, an older sister who's three and half years older than me and an older brother who's eighteen months older than me and I was third in the family.

*And you mentioned being born in Melbourne, was that where your family were from, both your parents?*

No, no my mum's totally English. She was born in Brighton in East Sussex and my dad is British, was British although he was born in Egypt and comes down a line I think originally from Malta and then his family went into Egypt but he met my mother in England when he was an actor and she was in a group of people where she came across him, I'm not quite sure how they met properly.

*And so how did you come to be born in Melbourne then?*

My family were ten pound poms. They lived in England and they went out to find their fortune so they went out to Australia and had me and then they came back again.

*Fascinating. And what do you know about your parents' decision to use thalidomide, is it something that they talked about? Who prescribed it for your mum?*

Actually it was in a liquid form for children and my brother was taking it as a baby because he was a very disturbed, as my mother said, he was a very disturbing child, he would cry all night and she couldn't sleep and he didn't sleep so the doctor prescribed Distaval for my brother as a baby and it was apparently ... one of my parents says it was in liquid and one of my parents says it was in pill form. My father's died so I can't ever get his side of the story anymore and I can't remember now which one my mother says because the story now changes unfortunately ... sometimes it's liquid and sometimes it's pills but certainly all she managed to do was get one or two helpings. She couldn't sleep so she went to the doctor and the doctor just said, "Listen, you know that stuff your son's taking, help yourself to that, it's really good, safe for you to take, it might help you." So she took it and when it ran out my dad went to the local chemist to get some more and it had already been withdrawn because this was now December '61, sort of half way through December '61 and they said, "No we don't, it's been withdrawn off the shelves, we can't supply it to you anymore, it's risky, we've heard about stories of damaging unborn babies." So she wasn't able to take any more.

*And so do you think they were worried then knowing she'd taken it when she was pregnant, do you think alarm bells went off?*

My mum went a bit crazy about it actually. She was convinced that she was going to have one of these babies that she'd heard about so she asked her doctor for an abortion and the first Doctor said, "Don't be ridiculous, of course you can't have an abortion," because it was illegal in those days. So she quietly kept it to herself and she went and found another doctor who told her that she should be grateful that she can get pregnant and that she was a very lucky woman to have children and that's what she would do and anyway she would just go through with the pregnancy and they can sort it out later, once obviously I was born. And then she went to a third doctor to abort me and he told her it was too late to have an abortion. I think by then she was probably past the three month period. I think she said she was about four months and he wasn't happy to give her an abortion but he had said if she had come earlier to him he would have given her the abortion. So she panicked all the way through the pregnancy about what was going to happen and my father just took no notice. I think actually she held it in she didn't tell him about her worries. And when she took thalidomide she didn't know she was pregnant although she suspected it.

*That must have been very filled with anxiety then for her, the same as you don't know you're pregnant and you go out and get blind drunk one night and then you live through the pregnancy thinking "Oh ..."*

Yes. Oh God yes. I mean she must have know she was pregnant because she would have been five or six weeks pregnant so she would have missed a period but, you know, she had a child who was only nine months old at the time and she wasn't sleeping so actually it's quite normal nine months after a child to not be regular with your periods anyway. So the alarm bells probably weren't necessarily ringing although once she realised she'd taken the drug during her pregnancy, the alarm bells were certainly ringing, yes, yes.

*Thank you.*

*And finally was it something that your parents could talk to you about later, they could talk to you about their decision to use thalidomide or was it always a rather awkward or cagey subject to discuss?*

Well no, they never did because actually I never lived with both of my parents after that, I only ever lived with my father and then he died when I was fifteen. So I was never able to ask the grown up questions that I so want to ask ... they're just not there.

*Okay.*

*Going on to talk about your birth, where were you born?*

I was born in a hospital. I always thought I was born in the children's hospital but I wasn't. I have discovered I was born in another hospital, I think it's called Alfred Hospital in Melbourne.

*And do you know how the birth went for your mother?*

I think it was a fairly normal painful birth [laughs]. I don't think it was necessarily hours and I don't think it was necessarily short. I don't think my mother really remembers it. She was completely convinced that something terrible was going to happen and, of course, my father wasn't allowed in the room in those days, you know, and also I was the third so it wasn't the same excitement. But when I was born they took me away and they told my mother I had no arms and no legs and she said, "I don't want to see the baby" because she said she that she knew if she saw me she would love me because I was her baby. So she knew there was going to be that bond if she saw me but she didn't want to love me if I had no arms or no legs because therefore I wouldn't have any life and so I think she was sedated for something like two or three days and always screaming, "Don't show me the baby, don't show me the baby!"

But I think I remember a story of my father telling me, I'm not sure how true it is though, that on the third day I think a nurse just took me in to my mother, just decided that she needed to see me to see if any bond was there and my mother took me ... and I don't think she breast fed me at that point, I was always bottle fed ... but she began to fall in love with me but they didn't trust her, the hospital didn't trust her. And I didn't know this story, I only discovered this story about three years ago but apparently I was then put in a foster home for two weeks so that they could stabilise my mother and get her back in the family and back to normal before they let me back in the home, or let me into the home but I don't know. My father never, ever told me that story and I have no records of anything so it's about really finding out but I just haven't sort of gone and found out yet.

*So where did you get that story from, that you just found out?*

Somebody interviewed my mother on the internet. His name is ... I can't remember his name, it will come back to me eventually, and it was called 'Days of Our Lives.' Was it called 'Days of Our Lives'? No that's ... what was it called? 'Our Lives' or something ... wonderful. And he interviewed my mother and I began to hear things that I had never heard about. It's like, "Where did that story come from?" but whether the interview brought it out in her or whether she just imagined it I don't know.

*So was he interviewing her about you or was it about other things in her life?*

He was interviewing her about being the mother of a thalidomide child. Yes, about her experiences.

*Although she didn't bring you up?*

Yes, but that was part of her experience because it was the final nail in the coffin of their relationship. My mum and dad were fighting from the beginning, I mean you know, they shouldn't have got together but they did and they had three children and when, you know, life is hard and then my father ... you know, we're a Jewish family, he was the eldest son of a Jewish family, you know, he's God in the family, you know, he's in charge and he doesn't do anything wrong and so apparently he said things to her like, "Well, we don't have anything like this in our family so it's got to be your fault" and this kind of, you know, blame went on 'til people really began to understand. And I think the way it's portrayed for many years, well the mothers took the drug, you know, it's their fault. There's that absolute dreadful guilt. My father didn't take the drug, he didn't take it, my mother took it so therefore it's her fault in her mind and it just destroyed her, completely destroyed her.

By the time I was three she was in a mental institution, she completely broke down and I think she was there for months and months and months and months. I've always had a memory of my mother and her hair was piled on top of her head and it was like a dark red, like a shiny dark red and when I first met my mum again when I was thirteen I was like, "My mum's got brown hair, I always thought she had red hair" and I occasionally said to my dad, "My mum's got red hair" and he just looked at me, like, took no notice. And I asked her when I was in my twenties I said, "Mum, did you ever have red hair?" and I told her this memory that I had of my mum sitting somewhere in a chair but it wasn't a chair, couldn't remember what it was, but she was certainly sitting with her hair piled on top of her head and it was red. But I couldn't get near her, I couldn't reach my mother, and she remembered coming ... she had no idea who we were, she had receded apparently or recessed or regressed to about that of a five year old and my father had had enough of it and apparently he brought us three children into the hospital, he was just sick ... he just thought my mum was just making it all up and he just let us into the bedroom. We all ran, obviously to jump onto the bed, I must have been three or four, and she was sitting in bed and her hair was piled up on top of her head and there was a red light in the room and she just screamed and screamed and the nurse had to come and they took us away. And so that must be the memory that I had and I don't remember the screaming, I don't remember anything, just this red hair with her hair piled on top of her head and not being able to reach her.

*What a powerful memory.*

Yes.

*And do you think ... was her breakdown entirely connected to your birth or was she already slightly mentally unstable in other ways before you were born?*

Well I kind of ... my mum's going to kill me if she hears this interview, I'd heard that she wasn't actually totally stable. She wasn't unstable, she wasn't, you know, breakdown material but she wasn't the easiest of

ladies in those days. But I always knew it wasn't me, Mikey, that was the cause of her breakdown, just circumstances were. So I always separated myself from thalidomide sort of I guess to keep that safety, part of me, it's not me but it was my physical me that created the final screw in the coffin.

But some years ago I had the privilege of speaking with her sister, who has now died, who died I think just two years ago and I said something and she kind of shook her head at me very gently and I said, "What are you saying?" and she said, "Your mother's always been like this" [laughs]. So it was done with love, you know, that's how my mother is. It's not that ... she doesn't make anything into a drama and I told my mum to her face she's a martyr so I think that for her she just held it all in and there's only so much you can take and ... yes.

*Before something starts to explode.*

Yes.

*And for the sake of the interview, because it's an audio interview only, can you describe your level of impairment?*

Oh yes, upper limb I've got arms about half length. One's a club hand which a certain gentlemen will find hilariously funny that I've said ... he likes to tell me it's club hand but it isn't. So I've got one almost normal upper arm with a teensy weensy lower arm, short, and the other arm is a short upper arm with a slightly longer lower arm, that one [MA indicates her arm] four fingers on each hand.

*Thank you. And what happened after you were born then? You said you didn't live with your mum, so where did you go immediately after you were born?*

I don't know. Apparently I went to a foster family.

*You said this foster family.*

Yes. I know nothing about this foster family.

*Do you know roughly how long that would have been?*

Two or three weeks.

*Okay. And then you went home.*

And then I went home.

*But not to live with your mum.*

Yes. I lived with my mum and dad. I lived with my mum and dad until I was about three and I remember fighting in the home, I remember it really strongly, her fighting, her sitting on a step crying so I must have been under the age of three to remember that. I seem to think that I was older so maybe she came back and they had another fight or something. But yes, so my mum broke down when I was three and she went to the mental hospital and I think she probably got better around the time I was four but she didn't come and live with us again, she moved to Sydney. So my mum didn't even live anywhere near us and we had housekeepers living in the home with us. So I think apparently we went through thirteen housekeepers in twelve months. My dad ... you know, we were out of control, completely out of control, and all our family, all my dad's closest family, brothers and sister were living in England because they were in Egypt and when the Suez crisis happened in '56 everyone was kicked out and so he brought his close family to England where he was already living, in Britain, because they were all British citizens anyway, and they were still there although he'd come to Australia where I was born.

So when I was six, he'd just had enough. My mother was in Sydney and we were in Melbourne which is over a thousand miles apart and he just picked us up and he left the country, put us on a boat and brought us to England which was quite a powerful thing to do because we didn't know we were coming so we came home one day and we were just put on the boat. That was the end of it, off we came, my mother didn't know where we were for about a week and he had cousins living in Australia and they didn't tell my mother where we were, she had to find out. But, of course, she only turned up whenever she felt like it so I don't know how long it took her before she turned up to discover we weren't there.

*[Laughs] I'm laughing, by the way, because a rabbit has appeared.*

[Laughs] and a child.

*And a child, yes.*

*And during all that time was your dad still working as an encyclopaedia seller?*

Yes, yes.

*And was that something he transferred over then, to the UK and carried on doing?*

Yes, yes. I know he was definitely doing that when he was a single father, a single parent, because he could do the hours around the children so I'm assuming he was doing that before we were born as well but I never thought of asking and of course I can't ask him now.

*What was he like as a single father? Did he do a good job?*

Brilliant. He was the most wonderful man; He had the greatest sense of humour. He adored the three of us, I mean he just adored us. We were so lucky we had a father who completely interacted with us, he adored

us. I mean my big sister has different stories of Dad, probably because she's the eldest and I'm the youngest, and so responsibilities were put on her that she still objects to to this day even though she's now nearly fifty-four she still has issues about that. But for me I was the youngest, I think he kind of favoured me probably because I was the youngest. We can't help it, you're always the cutest, you know how to play up, you know how to get exactly what you want with the way you ask for help and little arms are actually quite sweet as well so ...

*Yes. Yes, even cuter.*

So all of it, all of it. You know, I knew how to get my own way. I did it unconsciously, of course, but I could get my own way and I could wrap him round my little finger. My dad adored me and he's also written about our relationship. I always thought that over time that my special relationship with him was imagined because, you know, he died when I was fifteen as I've said and so then you begin to ... you grow another story in your head. But I read a letter he wrote about me to the psychologist which was done in 1973, I didn't imagine a single thing, my dad absolutely adored me and built a special bond with me that was an unspoken bond he and I had. And he was great with my brother and sister as well, don't get me wrong, but with me it was there, without doubt.

*Why was he writing a letter to a psychiatrist in 1973?*

Well, with settling in for the Trust I became a member ...you know applied to the ... I was a British citizen so I qualified under the deed of trust here in the UK and so that was it, it was a psychologist's report. And he added to that, he wrote what he thought was really important to add and I'm so glad he did that because now that I don't have him I can see what was really going on, really going on for him, not just what the psychologist was thinking was going on.

*That's very good to have isn't it?*

Yes.

*So when you came back to the UK, would you have been school age then?*

Yes. I was six and a quarter, or six and a third when I came, so we moved to London and we ...

*Central London or ... ?*

Yes. Sort of Gant's Hill, Ilford area. And I went to primary school here in London, or there in London for, it must have been a whole term. So we came to England in December so I went to school in London for that school term from January 'til April and my father just couldn't look after three children on his own, he just couldn't do it and go to work. There was no assistance anywhere to be had and single fathers was, like, unheard of and so he looked around for boarding schools. And because my brother, bless his soul ... as a baby he didn't sleep and he's a difficult character. He's a lovely character but very, very complicated and in



England schools are either girls or boys, it was very difficult to find co-ed but when we found a co-ed school one of us would do something that they would kick us out before we even got past the interview. Like, we found a school and they were just about to accept us and my brother found the gong and he whammed the gong and it went, "Bong!" right in the wrong time, all the children were in class and they asked him to stop and he wouldn't stop so it was like, "We don't want you in our school."

And we ended up in a Rudolf Steiner school and they said, "Yes, we'll take your three children [laughs], no problem, co-ed but the main boarding school won't have you." So we found another family and they were called the [Douchers ? 20:55] and they had six children of their own and they had ... they took the three of us and they had also living with them some children with learning difficulties and what had happened was, the woman who was in charge of the children with learning difficulties had gone on a two-week holiday and hadn't come back [laughs] and left these kids and I think those children lived with that family for about another two or three years at the time. And then there was an Arab family were living there as well, of three children, and then there was another family who were just living there.

But they all came just after we started living with this family, so we all lived in this big house by the school and went to boarding school. So by the time I was six in the summer term I'd come to England in the December and by April / May I was at boarding school at the age of six and living in this family and coming to Rudolf Steiner education which was nothing like I'd ever come across. We had half days, we went to school on Tuesday and then we went home again at lunch time and played. It was like, "What do you mean?"

*It's like learning through play isn't it? Isn't it how it works with those schools?*

Yes. You have proper classes and everything but it was just completely different. I mean nobody could read, nobody could add up one and one, you know, I was the brightest, most intelligent child in the classroom and I was only six and I could write and I could read and nobody could do that and they just thought I was amazing, the whole class thought I was amazing because, you know, I had short arms and they couldn't write and I could. But I very quickly lost my skills because nobody else was writing but I never lost my reading skills and then we all learnt to write by year four, we all learnt to write with a bamboo pen. We all went up the field and cut the bamboo and made these fountain pens and we learnt how to write calligraphy almost straight away and then we progressed to fountain pens ... pencils and then fountain pens.

You never wrote with a biro because biros weren't allowed in the school, even the teachers didn't write with biros or even ball point pens, everybody had fountain pens.

*Wow!*

By the time I was ten or eleven all my classmates caught up with me and then they all overtook me because I was a very late developer [laughs]. So having gone from being like, you know, the cool kid, I wasn't the cool kind anymore.

*One of the questions or the areas that we look at are whether or not people went to special schools but this seems to be a school that had both learning difficulties and ... it's just a school that took a mix of children regardless of age?*

Yes. The children with learning difficulties actually weren't in the school; there was a school for them so they weren't there. And, like any private school, if you have educational difficulties, private schools can't handle them because they have no resources for it. So there weren't really, at the time, any children with learning difficulties. What they did with me was they saw that I had a physical challenge and they allowed me to show them where my challenge was rather than them try to help me. So like you've probably come across with many interviews, we could actually do everything when we were younger and I think about the only thing I couldn't do was go to the toilet on my own.

I have no idea how I coped at boarding school but I do remember girlfriends coming to school with me so perhaps when I was in the classroom and needed to go to the loo the teacher ... well most children, they never went to the toilet on their own, they always went with someone. From my memory, vague, vague memory ... because it was a big school building, you know, in the local primary school there's like four classrooms in the infants with their own toilet, a sweet little toilet whereas in this big school building sometimes you had to walk all the way down a long corridor past five or six classrooms down some steps to the toilet. Then all the children went to those toilets, so you didn't just go there on your own, I'm quite sure you always went with someone and then someone would always come with me and whether they helped me pull my knickers down I don't remember. But I seem to remember by the age of eight I could do it on my own so I don't know what happened, they must have helped me.

But I lived with that family for a year and a half and then I moved to the big boarding school where there was probably about one hundred and fifty of us all living there, maybe less and I just sort of mucked in. And the only exception I had was my dentist made me have an electric toothbrush and I was deeply ashamed that I had this electric toothbrush. It sort of went up and down, it didn't go round like they do now. But it turns out that kids thought I was really cool to have this toothbrush but I didn't see it, I just saw that I wasn't cool and I couldn't ever get past that and that affected me I think. It affected my growth actually because I just thought I wasn't a cool kid and so people couldn't like me. Of course I always had friends but I never believed anybody liked me, which isn't true, and I know that's not true but that was my belief at the time.

But by the time I was twelve they built these new houses in Forest Row and it was 1973 so I was actually eleven and a half and we got our money. Compensation came through so my dad took the lump sum that I got and he bought a house with it. Many of the parents did, it was a great investment. And so we were able, as a family, to all come out of boarding school ... by this time he'd met a woman called Sonia who had actually come into my life by the time I was six and a half. But she was only twenty eight at the time and my dad was ... he must have been in his early forties, yes, he was thirteen years older than her and so she was there and so we'd go home for the holidays. But by the time he'd found the house in 1973, they'd built the house, we'd got the money, we all moved in together as a family unit. So my brother and sister came but my brother and sister were really disturbed about losing their mother, so my brother had actually left the family and gone back to Australia to live with her but that was an absolute disaster. And my dad flew in the end out to Australia and brought my brother back at which point my sister was demented because she was ten when she lost her mum, you know, a ten year old to lose their mum, it was just devastating for her. So she flew out to Australia and she stayed with my mother, living out in Australia, for the next three or four years until my father died. No, five or six years she lived out there ... gosh, yes, six years. No, no it wasn't, no sorry, no she lived out there for three years, three or four years, yes, but I never went back. My mum always said when I was fifteen I could go back to Australia and visit her but when I was fifteen she came to England.

*Okay, we'll move on to that part in a second.*

*Going back to getting the compensation through, do you know ... it probably would have been your dad rather than your mum, I guess, was involved in any of the Thalidomide Society meetings and the fights for getting compensation though?*

Absolutely. My dad was completely involved in it. I don't know what level his involvement was. We went to all the regional meetings, all the Society regional meetings. He did, and I remember he would sometimes take me and then once a year there was a big Christmas party and the whole family loved that, the pantomimes, the pantomimes on ice. The family all remember that and it was always something to do with me, we always knew it was because of me we were going and then there'd be all these weird people there without any arms and weird shaped arms, and really odd and it's like, "Why are we hanging out with all these people?" I was terribly shy; I didn't dare speak to any of them. I only really distinctly remember one person and that was Terry Wiles and the only reason I remember him was because he sang a solo. And I don't remember how he held the microphone because he hasn't got any arms, he hasn't got any fingers. I don't know if you've seen Terry, met Terry? He did *On Giant's Shoulders*. So I have no idea how but he sang this song, he sang *Silent Night* I think it was, on the floor. It was just like, "What are you doing singing that on the floor?" It was just like a voice came out of him. And then I remember *Jack and the Beanstalk* on ice and I'm absolutely convinced I met Martin Wale *at Jack and the Beanstalk* on ice and the reason I would have met Martin Wale, although I'm not sure it was him, was because he's also South East. I know I met Kate Perkiss somewhere along the line, she's South East and, funnily enough, by the time they did the Annual General Meeting as a weekend, the first one was in Wales and I was fifteen and my dad was still alive and my mum had come to England so she had come to England in the January and we went in the March, or beginning of April, to the Annual General Meeting in Wales. And I remember just looking around me this whole weekend where there were people like me but grown up. It's like, "Oh, I'm allowed to grow up" because I didn't know. Because I was such a late developer, it's like it just wasn't happening for me, I was really late but I realised that I could be like them and I was going to be like them and that was what my life was going to be like and it was really freaky. And the photographer came and took a photograph of me with my mum and my dad. It's the only photograph that I've got with me and my mum and my dad and then my dad died I think two or three weeks after that just very suddenly so it's the last photo we've got of my father as well. Really odd, a really weird situation and it's in one of those things you look through, it's in a little plastic thing you look through at the light and it magnifies it ... a little magnifying thing.

*Really magical.*

It is magical because it can't get damaged as well because it's a completely safe picture.

*And you knew at that point, presumably when you were going to these meetings, that you had been affected by thalidomide?*

Yes.

*I know you said it was odd seeing the people with the different shaped bodies but how did it feel to suddenly have like a new peer group, if you like, of people that were all affected by the same drug?*

It was really weird. I remember being forced to have photos taken of me so my dad said, "Oh, you've got to have these photos because you're thalidomide" or it was something to do with ... obviously it was

assessment for the damage. And I remember having x-rays taken and him shouting at the radiologist or radiographer, or whatever they're called, or the nurse because they put my arm on the table in a way that my arm actually doesn't go and he had a go at her but I was like, "Oh that embarrassing, don't embarrass me dad," you know, that feeling. And it's like, "Why am I having this?" and then having a test, like they sort of asked me questions like, "How many times does three go into seventy two?" It was like, "I don't know," it was like, "Fourteen times or something, twenty four times," hang on, yes, twenty four times. And that's right, yes? That is right.

*It is right. I had to think as well.*

And their great surprise that I got that answer right and I'm thinking, "Well, just because I've got short arms it doesn't mean I'm stupid. Why do they think I'm stupid?" And then they would do things like, you know, "Can you reach that thing on that top shelf?" "Of course I bloody well can," you know. And of course the more capable I was the less amount of money I was getting, you know, that's how they assessed it. You know, was I capable of pulling a chair over to climb on, did I have the mental alacrity I think to think of climbing up on a chair and stuff like that and puzzles and how quickly I could put a puzzle together and of course showing the agility in my fingers and all that kind of thing. And I knew that was going on and I knew it meant I got a day out with my dad which my brother and sister didn't get and there was always the jealousy of that. So I was aware of that.

When I went to the AGMs, the weekend ones, I was one of the younger ones, being, you know, August '62, and I was such a late developer so what really happened to me when I was sixteen when I went, my mother came with me, she brought her boyfriend and I was thoroughly embarrassed that she could have a boyfriend at such a disgusting age of forty-something.

*It's not right. [Laughs]*

It wasn't right [laughs]. And this was the woman I've never lived with so God knows, it doesn't matter what I was thinking, who knows what I was thinking she'd been up to all that time but I also remember her trying to control me and it's like, "You're not my dad and you don't know any of these people and stop staring at them" because I could see he was staring at them and it annoyed me. And I came across Martin Wale and Kate Perkiss who's now de Walker and we just became a threesome, a triangle of friends, and we still are to this day and we have other people who became the South East people but they are sort of, for me, they are sort of my childhood, even though they really started when I was sixteen. And I haven't seen Martin Wale for years and years and years but it doesn't matter, you know, he pops up suddenly on Facebook. And he'd be very surprised if he hears this interview and he hears me talking about him but he played a big role in my life, just of understanding that we've all got disabilities and he wasn't staring at me and he didn't care and nobody cared, nobody cared about the disability. I don't know how to explain it.

*No, no, it makes total sense, yes. There's nobody to judge you or you don't have to try and do that overcompensating thing and it's okay to ask for a glass with a straw.*

Well I didn't ever ask for glasses with straws. What I actually wanted to do was I wanted to help people or I watched people ... I remember I was allocated a room, because in those days if you said you were happy to share you got allocated to share a bedroom with someone and I was in the room and whoever I was supposed to be sharing with had brought her friend into the room and they clearly wanted to share together

and they were making the tea and I wanted to help them make the tea because it just looked so blooming difficult. And I remember thinking, "Oh, that's what I look like and I can't offer to help them make the tea because that's rude because I'm going to look like them" ... that's what I look like, oh that's interesting" [laughs]. That's really awful. But then I thought, "No actually they look quite cute." The way their bodies were bending over and they were doing things from their shoulders and I remember thinking, "Wow, people look really, really cute, maybe I look cute," you know, and it's like trying to work it out in my head but of course I couldn't because I had such a bad self-image by then. It was trashed, you know, I was such a late developer.

*What age was that, that age that you think your self-image was so bad?*

Oh, seventeen. By the time I was seventeen it was terrible and people, you know, within the community always think that I was really confident, attractive, could have who I wanted when I wanted. It's like, "You've got to be joking" you know, I didn't know how to talk to blokes at school. I mean at school, because I was such a late developer, you know at school the best looking girl goes out with the best looking boy and you go down in the list and I wasn't even looking at boys, I was riding horses, I was passionate about horses. And I was on horses 'til I was sixteen and then "Bang" one day I suddenly thought, "Oh, I'm going to cut my fringe, I'm going to cut my hair, I put blue eye shadow on." I changed; I got my period, that was it. Childhood was gone, it just went. It just went the same day as maturity came in. But the image was, you know, nobody's looking at me at school and my dad had just died.

*Yes I wanted you to go back to that actually because you said your mum came over to the UK ...*

[Interruption 07:26]

*So we'll go back just a little bit and tell me what it was like when your mum came back to the UK.*

Okay. Well what had happened was my brother had gone out to Australia and lived with my mother and that was a disaster. He'd ended up in a home for children with mental health problems and then my sister had gone out and my mother decided to come to England on a visit and she brought my sister with her but what she did was ... I was thirteen, not fifteen. She came for two weeks; she did a round the world trip so she came for through South America and stuff, came via England. Actually she must have come to England for four weeks but she took me and my brother to Greece on holiday for two weeks and I was taken away with this complete stranger. I remember her arriving. We all went to the airport to meet her, and she came with her boyfriend David. And my brother knew David and my sister was already there or ... I can't remember where my big sister was, I can't picture her in the car. But my step-mum was in the front seat, and wasn't yet married to my Dad. And I wanted to stare at my mother but for some reason I felt really guilty for my step-mum so I sat on her lap instead.

And I couldn't stop looking at this woman, this really strange woman and then she took me to Greece. I have memories of going to have a bath and my mum came in and washed me, and it's like, "Why is my mum washing me?" and I just let her wash me but I think she thought I needed washing, anyway so I let her wash me. I was thirteen, I was a very young thirteen year old and I was probably quite used to people doing things for me anyway, although I was becoming independent, or maybe I was still being washed at that time but anyway, she washed me, I remember the sponge and everything and the shower and the water. I think the excuse was the water was running hot and cold and it might burn me. And then I remember getting very

burned on the beach and I remember jumping into the sea and swimming and suddenly David yelling and shouting and panicking and a big ferry had gone by. What it did was it sucked the water out and threw the water on the rocks and apparently everybody had got out of the sea except me because I was swimming around and paying no attention and he raced in and he rescued me and I remember thinking, "Wow, somebody's just cared about me," not that my dad didn't care about me but anyway some stranger's just cared about me, but of course he wasn't a stranger.

And then my mother left again and then the next thing we knew was she said she was going to come and live in England and she packed up her stuff and she came. But in that time, after she had been to England, my stepmother actually left the family home. She didn't want to live with my father anymore. She actually didn't want to come and live down in Sussex but she'd come, she'd settled us all into the home, into our new home together and then she left so I actually then spent nearly two years living alone with my father and my brother. But my step-mum stayed in the area and it was all kind of weird and then my mother appeared and then she'd gone. And then my dad obviously wanted to get back with Sonia and he did and Sonia found herself pregnant but they'd already started getting back together again so they decided to get married. So even though they'd known each other for six, and this is now ... I'd turned fifteen which is nine years and they hadn't got married, they now decided to get married. So they decided to get married and I remember the wedding because I was fifteen and I was a bridesmaid and she was pregnant and my mum's got fabulous timing so when my step-mum was six months pregnant my mum re-appeared back in this country [laughs].

*I don't know if I want to hear what happens next but go on.*

Well, you know it's just my dad was ... obviously married to my step-mum now. But my dad had always believed in the family unit and his family unit at that stage was my mother and him and the three children and for my step-mother it was always very difficult, Sonia, because she always felt fourth in line or fifth in line, there was three children but by then she had begun to trust my dad. Anyway, so my mum's appeared, living in London and then the next thing I know is my mum, my dad and I ... because Sonia's too pregnant now, her baby was due. I think it was the very end of March and the baby was due on the 29th of April and we must have gone around the 28<sup>th</sup> of March to this first weekend Society AGM which was in North Wales and, yes ...

But you know, they slept in separate bedrooms and they end up in different hotels because my mum's bedroom had a mousetrap in it and my dad's bedroom had mouse droppings in it and then the hotel was going to put them in this double bed together. It's like, "No, no, no" so they went in different hotels and all this was going on. And then fortunately my step-mum went into labour early, she had my baby sister, my baby half-sister a week early on the 22nd of April. It was very, very exciting. In hospitals in those days, you stayed in hospital for a week. And life completely changed. My friends at school were saying, "You're not the youngest anymore" and "Oh my God, how exciting, you're going to be jealous, don't be jealous of the baby." I was fifteen and a half, why would I be jealous of a baby when I'm fifteen and a half, you know? But they all thought I was going to be jealous of this baby.

And the following week we were all getting the clothes ready, very exciting for the baby, she was coming home Sunday, we were going to get the baby. My brother and I were really excited there was a big fight in the home, I don't know, I'm fifteen and a half, my brother's sixteen and a half, screaming and yelling. My dad got involved and then suddenly he just went bang, fell over on the floor and we didn't know but he had angina, he didn't know he had angina and he was in you know, he had a massive heart attack and he just died there on the floor, within the hour he had died. So he died ... my little sister was born literally seven days earlier so he died around the same time she was born, a week later. And so the next day we went and

brought everything home and life completely changed. I mean I can't describe how completely different it was, he was my protector, he was my guardian, he was my parent ... can we stop?

*Yes, absolutely, yes.*

*Mikey, up until this point, so you're now about teenage years, what sort of medical interventions did you have from childhood onwards?*

When I was two, I might have been younger, they ... I'm not sure what my left arm looked like but apparently my hand was facing the other way so they kind of broke the wrist and straightened it and turned it inwardly or they stopped it being so club, I'm not sure. But anyway, they did something to it, kind of like a straightening of the left hand. And I was in hospital for a long time after that surgery. I remember that, I remember distinctly being in hospital. I remember being very sick in hospital. I remember the boy in the bed next to me. He had a broken leg and it was up on a stretchy thing and that's about all I remember and being there for ages and ages and then for years wearing these splints on my arms every night that my dad would strap me into these things in my arms. I don't know whether they were trying to straighten my arms or strengthen my arms or what they were trying to do with them.

*So you said you had to stay in hospital for a long time. Do you know how long that was, roughly?*

It was just weeks. It wasn't months and months like everybody else has done. It was just weeks. Weeks and weeks, but I don't know how long. Mum says it was ages but I don't know what she means by that either.

*And then you were saying about the splints, you had these splints on every single night.*

Yes, my dad put them on and I remember them coming to England with me definitely. But obviously they couldn't put them on me when I was at boarding school so it must have stopped. And I should think the Steiner education would have encouraged him to stop doing that to me anyway.

*Do you think they were painful to sleep in?*

They were annoying. They kind of stopped my hands from functioning properly, yes. I don't remember where they came to on me, if you know what I mean. I think I also grew out of them because if they'd been made for me in Australia when I got here and I was growing they wouldn't fit me anymore.

*And I suppose you probably weren't offered prosthetic limbs, were you?*

No. No I wasn't.

*Because that's mostly for people with virtually no arms isn't it?*

Yes. I didn't have any of that.

*And just generally going to see medical professionals, was it something you had to do fairly regularly, or not?*

Again, I think being at the Steiner school protected me from all of that because they do a form of eurythmy, it's a form of movement which helps you integrate into who you are and everything around you and so they sort of did that for me through dance because eurythmy is a form of dance movement. And they gave me extra eurythmy as well they said it was to straighten my teeth and I never believed them for years and years and then I discovered that other kids used to go for extra eurythmy to straighten their teeth as well.

*What's it called extra ... ?*

Extra eurythmy so you didn't just do eurythmy in the class with your classmates but we did extra and I always thought they were trying to get me to help my arms grow but of course it wasn't, it was something to do with straightening my teeth and of course they say your teeth of course are representative of your emotional well-being as well, so I think it was a form of, you know if you had crooked teeth your life was, you know, you weren't quite balanced and the idea was that they help balance you so that it helped balance your teeth. I think.

Yes, yes. Okay.

Very alternative.

*Yes. So you were never really offered prosthetics or any kind of technological gadgets to help, like dressing sticks or any of those kinds of things?*

No. I never had any dressing sticks or anything like that. I had the electric toothbrush which of course was probably the best thing that ever happened because I have fabulous teeth, I've been very, very lucky. I mean I was unlucky I had to have fillings but my teeth were always clean so I think I was probably quite acidic in my mouth to create the need to have so many fillings. But when we talk about prosthetics, it was only in my very early twenties that I wondered about prosthetics and I wondered what I would look like with long arms. So I found my way to Roehampton and actually was kept in for about three or four nights and I met another thalidomider there who unfortunately has since died. And I'm talking about the prosthetics department and they were intrigued by me because they couldn't believe that they hadn't come across me all those years and they said, "Oh, if we had come across you we would certainly have given you prosthetics." No, they'd have given, me, yes artificial limbs so that I looked good rather than go round looking apparently the way I was looking. And think that's why my father never let me anywhere near the hospital because he could see that I had my disability but he didn't see it as a disability. My dad saw it as a deformity but he could see that I could handle everything, you know, I could do things. It was just how other people reacted to me and he could see that having artificial limbs wouldn't change that so he just kept the medics and everybody away from me and let me just grow.



*And that was following when you went back when you were twenty, you didn't decide to take them up on their offer to work with you then?*

No I did, they made me a pair of artificial arms and they're in my attic today and my girls discovered them quite recently and they think they're the funniest things they've ever come across. Because of course my hands, my hands, aren't straight you can't just slide my hands into a prosthetic limb so you have to strap it on and then have my hands poking out so you can only ever wear it with long sleeves. And there is a photograph of me somewhere in the kitchen with the children with my false arms on which they love. They think it's really funny. We show it to people and no-one can work out what's wrong with the picture, what's different about the picture. They go, "What's happened ... how was this shot?" And they keep trying to work out what kind of photography it was and they suddenly realise that I've got full length arms, it's quite funny actually.

*So you did wear them from time to time then?*

Yes, but never out.

*And were they functioning arms, were they arms that open and close or were they purely just cosmetic?*

No, not at all. They were just cosmetic and that's all they did. Just to look ...

[Interruption 20:27]

*What about secondary school? So you talked about school ... you didn't really say where you went for the second part of your education, the teenage years.*

Okay. So when I went to the Steiner school, Michael Hall, it's actually from pre-school to eighteen.

*Oh, really?*

So you actually start in the classroom in what they call class one but actually it's the same as year two in the infants so you start a year behind, you start a year later than the normal schools, and it's obviously to do with age so it's the year you turn six. But the gap ... it's not a cut-off date of September, the age range can change from somewhere between June and October and it's usually something to do with your front teeth, your baby teeth. If you haven't lost any baby teeth you stay back a year and if you've lost your baby teeth or at least one baby tooth, I'm not sure how many then you can go into the first year of school but I'd lost loads of teeth and I was way ahead of everybody anyway so I went straight in at class one which was year two in primary.

And then you stay in what's called the lower school for eight years, so I stayed with my class, my actual class, we weren't streamed or anything, we did all our classes together. And the teachers came to us, we didn't go to the teachers and you have a particular teacher every single morning for two hours and in the very young days you have a teacher throughout the day, just like you do in primary school but as you get a bit older ... well you always get the French teacher, you get the German teacher, they teach you English, as you get older the Maths teacher but otherwise you have the same teacher so we stayed as a class together so I was really lucky.

When I was about six or seven I remember being bullied. The main door of the building, I was trying to open it from the inside and these kids, they were a couple of years older than me pushed the door open and knocked me back against the wall. I was very frail, very delicate, and they laughed at me so I went into a ball and crouched down on the floor and one of them kicked me and I remember just looking at them and I still remember them looking at me as they did it and they walked off, they never said anything so they must have been about eight or nine and I was six or seven. And about ten years ago, one of those men now, we were walking, I'd gotten to know him over the years and he just said to me, "Mikey, can I tell you something that I've never, ever forgotten about?" And he remembered being with the other two boys who'd kicked me and he says he's never forgotten it and he has felt terrible about that his whole life.

*I should blooming well think so too, to be honest.*

[Laughs] and I went, "Oh good, I'm glad you did" and he said, "I deserved that didn't I?" and I went, "Yeah" and that was the end of it. I didn't bless him with my love or say, "Okay don't worry about it, I survived," it's just like, "Yes, I'm glad you felt crap" and that was the end of it. But I didn't get bullied at school. I remember we had a real bully in our class and people still go up to him today and say, "I hated you, you were such a bully." And around class five, which was year six, he decided to start calling me Captain Hook and we were in eurythmy of all bloody classes and there was another bloke called Simon, as well as him and they both turned round, and they obviously had planned this together and they called me Captain Hook and I remember just thinking, "Oh, I'm getting a nickname. I don't really approve of that nickname, I'm not sure if I like that" and I looked at them and I just laughed because I thought it was funny to get a nickname. And he's never forgotten that either because I said to him recently, because he and I are quite good friends, "How come you never bullied me?" And he went, "I just couldn't, you just weren't a victim, you weren't bullying material" and there were a couple of kids in the class who we bullied mercilessly and he said "Why?" and he said, "Because each time he came near them they cringed." And he said, "You just didn't" and I said, "No, because I've always thought you were really entertaining." I still do think he's entertaining.

So I think that the bullying thing, there was never gangs of kids at the school anyway, so I never had to ... you know, you hear these reports of things that happen like that but it didn't happen like that for me in our school and the individuals who did bully just didn't bully me, they left me alone.

*What about any other kind of attitudes towards your disability or anything you couldn't do that other people could do. Did you encounter any prejudices against you at any point during your school years?*

In school? There was the teachers who kind of thought I was kind of really cute, you know, and they would say things like, "Oh you're amazing" and I'd just sort of think, "Go away, leave me alone" because I wasn't amazing, I just did it, I wasn't trying to be clever, I wasn't trying to be anything, I was just writing and I was running. I was a very good runner, probably at one point I was the fastest runner in the class even though I was the shortest. I was just very, very sporty and very fit because I rode horses all the time. But that was

really the worst attitude. I don't remember any teacher ever saying that I couldn't do something, I mean it wasn't that kind of school.

In fact when we were in class six which is year seven you got to do what they called woodwork, it was carpentry obviously, but it wasn't carpentry, it was woodwork so we were given blocks of wood and a rasp and we were taught how to make a dibber for example, you know, to dig into the garden or you made a darning egg and it was all about geometry, symmetry. And there was never any question that I wouldn't do any of that and it turned out that I actually had a gift for woodwork that developed very, very quickly but what I couldn't do was, you had a mallet, you hit the gouge with the mallet, wooden mallet but all the mallets were too big for my hands so once I'd finished making my dibber, which my Step-mum still uses today she loves it. And her daughter made a dibber as well, my half-sister, she doesn't use that one, she says it's not as nice as mine and it's thirty-four, forty years old, my dibber and still using it.

But I realised I needed ... so I made my own mallet and it was on the end of the row of all the mallets, it was Mikey's tiny mallet. And people would use it for delicate work, they liked it and you know, the boys in the class were good, if you were planing a bit of wood or doing something and they could plane the bit of wood in maybe three strides down the desk and I'd sort of go ... you know, go along and I remember so distinctly one of the boys at school called Nipper, he just went, "Right, out of the way Mikey" and he just grabbed the plane and the job was done and that was it, he just went off and did something else and I'd just carry on with my work. There was never any, "Can I help you, would you like me to do something?" It was, I don't know ...

But I discovered that my class was actually quite proud of me. There was a kid at school and I opened my desk one day, because we had desks with lids, and I opened it and it was not in the order I'd left it quite, just something was slightly ... somebody had clearly been in my desk and not put it back properly and the really cool kid of the class came up to me she said, "Mikey, sorry if we left your desk in a mess, I'm really sorry but my grandparents came to visit and they always want to see your schoolwork, they're so fascinated. So I showed them your books and we just didn't have time to put them back again properly, I'm really sorry." And I was, "What do they want to look at my books for?" because they were actually really quite esteemed people in the school so I felt really quite proud that they wanted to see my work. But then I knew it was because they thought I was disabled so they were impressed with me and that kind of annoyed me at the same time. I felt proud but annoyed in the kind of same way that I feel now when people tell me how amazing I am and I feel really proud that I'm amazing and then I'm annoyed because of course I'm not amazing, I'm just doing what anybody else is doing.

*I think it's good to be proud of the things that you do that are above and beyond those things as well. It's just that if people always couch it in, "You're so amazing that you've done that given that you have a disability."*

Well, well yes.

*Whereas if you've done something amazing then you should be told it's amazing, not with the qualification that, especially given that you've got blah, blah, blah ...*

Well I guess if you ... I don't know, it's like, you know, you make a choice how to live your life, well you live your life generally to your character, don't you? So if you're an outgoing character, you can't help yourself or if you're a chatty character you just can't help yourself, your mouth opens and words fall out. And there's people who are just like that and it's got nothing to do with necessarily their upbringing, some of it's to do

with their upbringing but you get very silent people in very loud households and you get very loud people in very silent households. And I think those of us who live our lives with respect and we go and apply for our jobs and we do those things and we just get on with our lives, it's not that we don't not think about it, we just lead our life, we don't go woe is me. So what they're saying is, they're really proud of us for standing up and doing that but what I'm actually saying is, actually it's not about being brave. If you're a brave person ... to me a brave person is running into the burning house to rescue somebody, it's a conscious act, whereas the way I live my life or certainly lived my life for many years was not a conscious act, I lived it unconsciously like most people I lived it. It's now I'm beginning to feel brave where I'm consciously choosing how to be and how to behave and how I stand up for myself now, that's conscious and that's where I now feel that I'm a brave person whereas I never felt that before.

*That's interesting. At this point of time when you were in your teenage years did you continue to live with your step-mother then?*

After my dad died, oh God, yes I lived with my step-mum. My brother left the home and I can't remember where he went. He went to live with my mum and then I just can't remember, I think he went to Germany where he lived for years. But I lived with my step-mum for another year and a half. So my dad died in the April and I think I suddenly grew into a woman about eight months later, nine months later like it was just instant, overnight. I cut my hair, cut myself a fringe, put my make-up on got my period, bang, I had changed. And life was becoming very difficult with my step-mother because she was very anxious, very angry very ... all those things that you are when your husband has just died on you, you've got a brand new baby, you've got no support, you've got no income coming in, you realise the house you're living in isn't even yours now, it belonged to me suddenly, so we had lots of really bad times, it was, it got ... you know, my dad wasn't there to protect me from her, from her rages and it's very ... can you just switch it off?

*So we were talking about life at home with your step-mother after your father's death.*

Yes. Well, you know, I was fifteen and a half, fifteen and three quarters and as I said earlier life ... you know, I suddenly began to grow up and so I became a teenager. I think I was probably ... I don't remember being a difficult teenager and I'm sure all teenagers, everybody says that they don't remember being difficult teenagers. But we had ... life got very, very hard. It became very different and it became very, very hard. I had this adorable little half-sister who thought the sun shone out of the back of me and, in the end, when I was seventeen I left home and I arranged it with the tutor at school that if I couldn't handle life anymore the way it was, could I move in with my best friend at that time, who was called Hella? And my mother actually stepped in. it was the first real act of anything that I felt that she did as a mother and she took that responsibility and said that she would pay towards me living with this other family. But this other family actually weren't living in a normal way either. She was boarding in her own home so her parents lived overseas and this American family were living for free in her parent's house and because they were living there for free they looked after her and her other sister, she had a younger sister. And we were all terribly, terribly close. This woman had two boys and a girl, one of the boys got expelled from school, and then there was my closest friend who's nearly a year older than me but because she's the beginning of September and I'm at the end of August, you know ...

*Oh, you were in the same school year.*

We were in the same class together. It was brilliant. And even though they had weird endings with the age group, you know, she came along a lot more advanced than many of the Steiner kids as well so that's why she ends up in our class.

And I just moved out. One day I came home and I couldn't stay, you know, it was so awful. And my big sister had visited me and had given me a five pound note to put on my window ledge and I had a special box on the window ledge. "If you ever need that don't tell anyone you've got it, it's just yours". I just took that five pound note and I just went on the train and I went up to London and found my mother ... didn't know how to get round London but I found her and we put into motion what I'd set up at school.

So then I lived with my best friend and this weird American family for, I don't know, a whole school term, two terms ... I can't remember what it was. It was just wild and out of control and by then we had another friend who I'm still very, very close to. And there was the three of us and my friend who I was living with didn't have any guidance or guidance from her parents, I had nothing and my mother, I don't know what was going on there and my step-mum ... there was just barely any connection. And this other friend, she was also a boarder and it was just like, there was just nobody for us to turn round to and say help and we were all very lost and just doing the best that we could. And in the end I just said enough and I went to Israel. I just couldn't do anything else and I lived out in Israel for two years on a Kibbutz. And I was on a Kibbutz and I did various other things. That was when I found my worst discrimination actually, in life, because I went to the Kibbutz agency in Tel-Aviv and they said, "No, no, no, you can't go on a Kibbutz" or they'd said that to me in London and then they said it to me again in Israel and I said, "Come on, send me to a Kibbutz." So they did and I walked about three kilometres up a dirt track with my bag for the interview and then you get to stay and they said, "Sorry, we're just not going to accept you, we just don't think that you can get dressed quickly enough in the morning to do work" and they watched me walk. It was like this three kilometre walk again, with this really heavy bag and I'd never come across it, nobody told me I couldn't do anything. I was just shocked.

So I worked in Israel, did some work for the hospital, bit of research and then eventually I went to the Jewish agency and there was a very big, tall, American Jewish woman there who was going off to a Kibbutz and she said, "Oh you come on our Kibbutz it's a great Kibbutz" and she told the Jewish agency they were going to send me and when the Jewish agency said no they weren't she said, "That's what you think" and, you know, Americans don't take discrimination, they just didn't take it then either. And she got me on the Kibbutz and this Kibbutz tried to get rid of me as well. They said, "If you can't do any work we'll remove you, you'll have to leave." So they never put on me on the rota. I went to the rota every day and it was also an Ulpan so if you were Jewish you could learn Hebrew half the day. So what you did was you learned Hebrew for five hours a day and you worked for three hours in the afternoon and then the next week you worked for five hours in the morning and you did study for three hours in the afternoon. You do that six days a week obviously.

And I was never on the rota and I think on the fifth day I was called by this big tall American woman and she said, "Listen, some people would like to talk to you" and they had all gathered together, all the Americans on the Kibbutz who were on the Ulpan ... there was about ten or twelve of them, I think some of them were leaving so some were from the last group who had stayed over and they got together and they said they had told the Kibbutz they had to put me on the rota and if they didn't they would all leave. And the Kibbutz actually gets more money for when they have Jewish volunteers on the Kibbutz, on the Ulpan. In those days they got paid by the Israeli government for us being there so we were income for the Kibbutz but they still didn't care about my income but they were very afraid to lose all this income and they put me on the rota and they said, "Can you iron?" of all the jobs to give somebody with short arms they gave me ironing. I said, "Yes, I can iron" I love ironing and I used to iron all the aprons and I worked with a very interesting woman who had been ... she managed to survive Auschwitz and then she'd gone on one of the boats and then she'd ended up in Cyprus, in one of the camps in Cyprus with the British and she was literally one of those on the Exodus, on an Exodus type boat who had made it to Israel and as she landed on the shores,

the clothes had, you know, she'd got the Kibbutz clothes on and disappeared into the country. And all of those people had got together and formed this Kibbutz so they were very angry people and they were survivors but they couldn't handle disability. And so a lot of the time I spent on that Kibbutz I was accused of not doing any work and I found it ... God know why I stayed on that Kibbutz as long as I did.

And there was a wonderful girl with cerebral palsy who was born on the Kibbutz so they couldn't throw her off and one of the volunteers came and he was Iraqi, Iraqi Jew, and he fell completely in love with her and her parents just said, "What are you doing, you can have anybody you want, why do you want our daughter?" So there was that really poor attitude on this Kibbutz and I thought that's how all of Israel was. And I discovered that Israel wasn't like that, it was just this Kibbutz but I didn't know that so on top of how difficult life had been after my father died, with that it just was not a good set up for me. But in a way it was ... I can't ... it was what my life was. And I came back to England and it was a struggle and I was a single woman living in London trying to get ...

*How old would you have been then?*

When I came back to England I was twenty one. And I went on a ... I trained as a computer programmer. I did a TOPs course. You could do ...

*It's just about what I was going to ask you next, about further education.*

Well, there was something in the eighties called the Employment Rehabilitation Centres, E – R – C and if you were a disadvantaged unemployed person, so basically if you were unemployed and then disadvantaged, say, in those days if you were black or if you were disabled or, I can't remember what else qualified you, you could go on these things. So I went and there was a thing they called a computer and it wasn't switched on and we kind of like, "What's this?" and we sort of pressed a button and it came on and it was a word processor and we learnt how to use the word processor and then we taught people who came in and they said, "Oh, you've obviously got technical skills, you should do a TOPs course in computer programming" because I had no other qualifications. So I went off to Queen Elizabeth's Vocational College for the Disabled.

So it was the first real time I was thrown in amongst disabled people and that's when I began to really grow because there were all disabilities, they weren't thalidomiders, there was, you know, I mean the deaf community just took to me. And I remember saying, "Please can I learn signing?" and they said, "No, don't bother," they weren't interested. So I just said, "Well you'll just have to read my lips" and they said, "That's what we like to do." There was a hundred and twenty men there and forty women and so it was just heavenly and for one of the first times blokes began to really fancy me or that I noticed blokes were fancying me. And they just didn't care, they didn't care that I had a disability and I didn't care that they did either; it was like, really weird. There was only one bloke that I actually really liked at the College and unfortunately he had a girlfriend at home so nothing ever came of it but he was the only one who I was attracted to. But lots of the blokes were attracted to me and that was really important for me because it was like, "Oh my God!" But I still didn't know how to ... they were just naturally attracted me, I wasn't doing anything; I wasn't playing any games with them. And that helped me really grow, that helped sort of take away lots of the pain that had gone on in the previous years. But I just got wild again when I was there and they didn't want me back. My six month course was over, they didn't want me back.

*What do you mean you got wild, what did you do?*

Well it's really odd because in those days disabled establishments were run by ex-police officers and people who saw us as really third class citizens and at the time the head of the year, or head of the school or head of the college was an ex-policeman or an ex-sergeant or an ex-something or other and he was just horrible, he was a horrible, horrible man.

And it's like, you know, there was the women's dorms, women's building and the men's building and the men weren't allowed in the women's and the women weren't allowed in the men's but if a bloke walked you to your door they had to leave by ten o'clock, you couldn't stand outside the door. I mean, you know, we were twenty-something, we just weren't allowed to do things and because we were disabled you know. Sex doesn't happen amongst disabled people you see and if it does then it's because somebody's taking advantage of somebody else, you know, it's certainly not consensual. And certainly there were women there who, it wasn't consensual, you know they were incapable of ... but you know that's going to be in any group it's not because they're disabled. It might have been their disability that caused it but actually it didn't because there weren't ... there wasn't anybody there with learning difficulties, it was just for the physically disabled people there. And that was a great eye-opener as well, dealing with people with epileptic fits suddenly, learning to dance in a disco and do really naughty things. You couldn't have flashing lights because it would set off epileptics and you couldn't have a very bassy bass because it would set off the epileptics as well which was really unfair for the deafs, the deafies, because all they could do was hear the beat of the music. So what we would sometimes do is, we'd all have this agreement between ourselves, within a gang obviously and when the slow music came on we danced really fast and just get the deaf people dancing really fast and they had no idea what was going on. It was so much fun, we were just so cruel to them [laughs]

It was good fun, it was really good fun and we all learnt and we all got on with each other and there was amputees, people who'd lost their limbs in motorbike accidents, that was the main thing. Of course there wasn't the wars at that point, you know, our British boys weren't being blown up particularly anywhere.

And that was very good and then eventually ... I was living in London, I can't remember ... in different flats with different people and I finally bought my house in Sussex in 1984, I think it was, 1985 I came back.

*And were you working then, what did you?*

I was working. Well, ironically I was trained as a computer programmer and I applied for many jobs and they all said things to me like ... well, I only got a couple of interviews and I was told in both of them that I couldn't type and I was sent on my way. Somebody like me clearly couldn't type and at that stage of the game I was already sixty words a minute and at my fastest I got up to ninety words a minute, approximately ninety words a minute. So it was absolute discrimination but I didn't know what to do about it in the eighties, I had no real family to go and ask for help with. I just didn't know how to cope or function within the world.

And you know, being a member of the Thalidomide Trust ... what I actually did was, I started to temp, I walked into an agency, a job centre, and they said to me, "Oh you need to see a Disability Employment Officer, D – E – M or D – R – O or Disability Rehabilitation Officer which I found so insulting. And I said, "I don't want to see your Disability ... I just want you to give me a job." Anyway, I came back on the Thursday and I met them and he was so wonderful and he said, "Oh my God, we've got a vacancy going in the Job Centre" and he gave me a job in the Job Centre and so I interviewed people as they came in. Job Centres were big things in those days and it was on the Edgware Road and it was so busy and I got hundreds of letters, thank you letters from people who when they got their jobs they wrote in, they faxed in, they thanked me for the jobs that I gave them.

Because it was Civil Service, you could only work three months in the Civil Service as a temp and then if you wanted to stay longer, you couldn't. You had to go away and come back again because otherwise they had to employ you on a full time basis. So I went off and so because I'd worked in the Job centre they knew what I was like and I got great jobs, I went all over London doing administrative jobs. I didn't do anything with my computer programming. And I wrote to the Thalidomide Trust and I said I need to buy a house, I need somewhere to live to be secure and they said, "No, because you're temping we're not prepared to give you a loan of your money." And I didn't know what to do again and I went around for about a year and a half really confused because I had sold my house in Forest Row, so my step-mum had security and I had all this money in the bank somewhere and it wasn't doing anything and I began to notice that property was suddenly beginning to be valuable and I spoke to a beneficiary in the Trust and I said, "What am I going to do?" and he said, "Of course you should get a mortgage" and he told me what I needed to say to the Thalidomide Trust and showed me how to stand up for myself. I didn't really, consciously ... you know.

And so the Director at the time came to visit me in my flat in London, it was my best flat I'd ever lived in and he wouldn't even sit down on a chair. And I lived with three other girls who were gross, they were so gross. I was so unhappy living there and I just enclosed myself in my room. And of course I wasn't going to take him into my bedroom which was actually really nice but the public space wasn't nice, even though I'd cleaned it the day before, they'd come back at one o'clock in the morning, they'd just trashed it, they'd just made it so filthy with tissues out of their noses. It was just nasty, they were nasty, all their clothes everywhere, and I tried to clear it up before he came in. Fortunately he reported back, that, "We couldn't have" ... I think it was something along the lines of, "We can't have one of our beneficiaries living like this" and they agreed to loan me four years in advance from the Thalidomide Trust, which was all I needed. And I came down to East Grinstead, which is four miles north of where I live here, and bought me a house for forty thousand pounds, which was all I could have at the time, along with the other money that I had and I just ... that was a big start for me. I had my own security, which I'd lost, the moment my Dad died the insecurity in my life was just so massive. So I got security finally when I was just turning twenty five.

*That's very interesting, thank you.*

*And relationships. Boyfriends?*

Well no, I fancied someone in Israel, he didn't fancy me. I fancied somebody else in Israel and we had a bit of a physical relationship but we didn't speak any languages the same and I don't really know what happened there, and then, no relationship. And I was crazy about a man in England, really crazy, but he had a real hang-up about my disability and I knew it and it was terrible and that was damaging in itself because almost as if all the bad stuff I believed about myself he told me was so, this is so. "Yes, we don't like people with short arms, we don't like disabled people," you know, it's all that awful you know, "Yes, we look at disabled people as different." Nothing empowering in anything he ever said to me.

And then I was aware that this bloke fancied me when I was about twenty-five and it's like, "Well I don't fancy him" and occasionally he would pop into my life and disappear and when I was about twenty-six / twenty-seven, I'd gone somewhere and I'd seen him at a party and he had a girlfriend but he was still looking at me and he came and he said something to me and I was like, "Oh, I don't think you should have said something like that to me, you've got a girlfriend" and kind of disappeared off and kind of began to make me think a bit differently. But he liked me for three years before he found the courage to ask me out. And I just knew, and my girlfriends said, "It's his Birthday, please come to his party, he would really like you to be there" but he hadn't had the courage to ask me. And I could look back bitterly and say, "He was too afraid to go out with me" or I could go, "He was a bloke who really fancied me and he just didn't know how to do it" you know, just like you fancy anybody and I chose to take it that way and I went to his party and we



had a four year relationship. And it was good, we lived with each other and he lived with me in my house. He had a place but we didn't live in his place. But in that time I went off round the world, I back-packed round the world. By then I had a really, really, really good job. I was working in Forest Row; by chance I think my company moved to Forest Row ...

*What were you doing, what was your job?*

Well, I came in as a temp, because I'd moved to Sussex and I'd carried on temping but they realised very, very quickly that they wanted me to stay permanently. It was a publishing company and I will never forget, the most I'd earned in a job full-time was five and half thousand pounds and he said to me, "How much would you like to earn, what would you like your salary to be?" and I thought, "I want to get something like six thousand or something." This was quite a few years ago [laughs].

*Yes, exactly.*

And I thought, "How on earth do I ask for that?" or, "I think you have to ask a bit more and then let him cut me down" and I thought, "What if I ask for seven?" And I thought he would kick me out and tell me there's no job. Anyway, I thought, "I wonder if I have the courage to ask for seven, I wonder if I'm brave enough and then he can cut me down to six and a half, sorted." And I came back to meet him and he said, "So, Mikey have you been thinking about it?" And I said, "Yes." And he said, "Have you got a figure in your mind?" and I went, "Well" and he said, "I'll start you off. Why don't we start you off on eight and a half with a review in three months' time?"

*And you weren't going to say no were you?*

And I just went, "No, all right then" [laughs] and he went, "Good, right, off you go then" and I went back to work. And I became a manager in the company and I programmed all the computers, well, there was only one computer at the time ... there was two computers, bought in more computers, networked them, there was no internet at the time and it was the beginning of networking, you know, could have like, home things within the company. Anything that ever went wrong I fixed it, I was the administration manager. I had five staff, it was just brilliant and I was deeply, deeply stressed working there and had no idea how to handle my stress and my boss, the editor, the managing director of the company didn't know how to handle his stress either and the whole thing got out of control.

And in the eighties, you know, stress was becoming the in word but I didn't really know it at the time. And I remember sitting on my bed at three o'clock in the morning crying not knowing what was the matter with me. And in the end I left, after four years. I earned ... I was on such a silly, funny pay scale by then. It was like, you know, five and a half thousand, I mean that was almost a month's salary, do you know what I mean? I was just earning such good money because I got paid really well for everything I did and I was typing ninety words a minute and there was nothing that anybody could ask me to do that I couldn't do in that company. I could just do whatever was needed. And then I left and went round the world for two years and that was life changing again and set me off on another direction.

*You did that on your own?*

I did it on my own. The boyfriend I had just wouldn't save the money and go. And as wonderful as we were together, when we were together he didn't work and as soon as I went off travelling round the world he started working again. I couldn't get him to go to work. His mother used to nag him to death. He was just lazy, he just wouldn't go to work, or he'd go to work and come back. But as soon as I was gone he went to work. Properly, like eight in the morning 'til eight at night. Then he came and joined me in Australia and we travelled round Australia for six months but because he'd gone to Australia House to get a permit in a trench coat, with a beard they wouldn't give him a working permit, they only gave him a six month tourist visa. I mean just really stupid things like that and all that makes you begin to think things like, "How serious is this person?" But he did fall in love with me, he did want to marry me and I didn't want to marry him and I didn't want to have his children.

Well, he ran out of my house one day saying, "It's over, it's over" and tried to come back, it's like, "No, no, it's over, you have to go." And it's very scary for anybody going back on their own again, particularly as it had taken me so long to find someone. But I knew I couldn't spend the rest of my life with him.

And then I was out about and I was floating around the pub one day, waiting for a girlfriend to arrive and in walked Paul.

[Break in interview 25:37 – 25:58]

*So what happened when Paul walked in?*

Well it's really funny because actually I'd been looking out the window and I saw this man pull up on a motorbike and I turned round to my girlfriend Hella and I just said ... and Hella's the one I lived with when I was still at school and I said, "Oh my God, who's that?" And she said, "Oh, that's Paul." "Okay." Completely forgot about him and I was in the pub one day and I saw him and I went, "Who's that?" and she said, "That's Paul, you asked about him once before." I said, "Did I really? Gosh!" And I'd forgotten the man on the motorbike, obviously 'til I'd made the full connections.

And then I went off to Israel and when I came back ... I was on holiday, and when I came back I was going to meet Hella in the pub and I got there early and Hella was late and it was early for us ... I never used to go the pub before half past eight / nine o'clock, I was always sort of a later drinker but for some unknown reason we had decided to meet at half past seven but I'd gone at about seven and I don't why I went at seven, I can't remember why. And I walked into the pub and I saw a bloke who I hadn't seen for two years because I'd been travelling around the world and I'd come back and I've now broken up with the ex-boyfriend and I just went, "Oh my God, Skaz!" and I just shot down to the other end of the pub to say hello to him, "Where have you been?" "Oh, I've been in Nepal and Thailand and Malaysia and Singapore and Indonesia and Australia and back again." "By the way, this is my mate Paul, say hi, this is my mate Paul", it's like, "Oh," you know, it was the bloke from the motor bike, it's just like, you know, I just became dumbstruck. But I managed to sort of regurgitate the words, "Hello" again and he said something to me and I said something back and I realised he wasn't much of a talker and I disappeared again. And then my girlfriend turned up and we must have had a very silly night and all the rest of it.

And then I went to the pub again, early, and he was there again and it's like, "You're still there" and I just remember, like, going up and always saying hello to him it was just, I could not let this person go by without saying hello to him. And he said something really, I don't know, in only the way that you know, turns you on to that person and it just froze me in my tracks and I remember just looking at him thinking, "You just, you can't go far, don't go away." And I was single and for some reason Hella never came, I never saw her in

that pub again, but I had another girlfriend, two other women who we'd gotten to know each other because we were all single in the pub together and there was a couple of blokes who were single but none of us all fancied each other and suddenly a bloke came along and fancied my girlfriend and it was really odd.

And there was one woman who drove everywhere, because it was, you know, crazy single days and suddenly there was a party in a field and it's like, "Who's going, are we going to go to this party, yes we'll all meet up" and we all met up at the pub. "Let's go to this party" because we're all still in our very early thirties at this stage and we all raced out to her car and I hesitated because I wanted to see where he was going to sit and he took the front seat. And I was like, "Well, that's no good, taking the front seat because you can't sit next to someone in the front seat, can you?" you know? And I went, "Where am I going to sit?" and he just patted his knee, so I jumped on his lap in the front seat, went down some country lanes and ended up in this party in this field where I end up on some stage singing and dancing with other people and being very, very silly. And a girlfriend hauled us home and he was in the car and I was in the car and when we got to East Grinstead I staggered out of the car and she said, "Right Paul. I'm going to take you home now" and he went, "No, don't worry about it, I'm going to stay here." And he stayed and that was it. And then we, you know, you play about for about a few weeks, you're not sure what's happening and then about four weeks later I had to have surgery on my foot, I had a lump growing on my foot, a growth. And the doctors needed to cut it out. And they said I could only go home if I had twenty four hour adult supervision. So I asked him if he'd like to supervise me for twenty four hours. And he just didn't leave; he didn't leave for another thirteen and a half years.

*Wow. And what did he do, what was his job?*

He was ... he is a mechanical design engineer. A really bright, bright man. Nobody knew he was bright until he started working in an engineering company as a welder and they sent him off to college and discovered that he was incredibly brainy. He was an otherwise very ordinary man, very kind, sweet, you know, he's like ... that fireplace I have there, after he built that ... it doesn't look so good now because of the wood around it. But he built that and he'd sit here and he'd fidget and I would go, "What's the matter?" And apparently one of the bricks is upside down, and you can't see it, it's round the side and it's like, "Let's not worry about an upside down brick." He's a perfectionist. And lots of stuff around this house he's done. So it's funny because I can always employ somebody to do handy jobs around the house but when he does it, he gets the dustpan and brush afterwards and he cleans up the mess.

And I lived with him for over thirteen years, we know how to clean up and move around each other. But, you know, he has his own dreams of what life is and what life should be and I have mine and they began to not match. The children came along and I just became obsessed with the children, you know, I just could not believe that I had children. It was like ...

*Rewind a bit.*

Okay.

*So how long had you been together when you first got pregnant and did you plan to get pregnant?*

Yes, I definitely planned to get pregnant. I think we'd been together ... hang on, I was thirty six when I had Maddie and I met him when I was thirty two, Jessie I mean. So I was ... yes, four years, we'd been together

four years. And I said to him right at the beginning, when I realised we were falling in love with each other. And I said, "Listen, I want to have children" and he said he didn't. He said he didn't want to have children and I said, "Listen, I don't want to get into a relationship that's not going to go anywhere." You know, I wasn't talking about marriage, I want to have children. And I don't remember talking about it any further that day. And a few days later he mumbled something about it's funny how the idea of having children can grow on you. So that was kind of a commitment to each other in a way.

And he wanted to get married immediately but he was the kind of man who ... that's what you did. You got a girlfriend and then you got married immediately. And I remember saying to him, "You don't have to get married." I can't believe I said that to him! And so we didn't get married and then decided to have children and I came off everything. And then you wait, don't you, no contraception left inside of you, all the rest of it and then I got pregnant straight away, instantly, as soon as we sort of said, "Let's go for it." We got pregnant.

And then it became complicated because my firstborn, Jessica, became breach at thirty three weeks. She just went ... and I remember thinking an alien was about to come out and we went to see the midwife and she was breach. They couldn't turn her so what then happened was they said, "You're going to have to have a caesarean" and I said, "I don't want to have a caesarean" but the baby wouldn't turn. And then it got complicated and then you go in and you have your caesarean and a really stupid doctor, a really ignorant stupid doctor, saying, "This is how you get up out of your bed." And I said, "Well, I can't do it like that because I don't have the arms to push myself up and turn over." "Well, if you don't do it that way, don't expect anybody to give you support" or something. And, of course, my scar tore, I got a haematoma. So instead of being in hospital for three or four days it turned into eight days. And then my baby didn't drink and I had breast surgery and so it created serious breastfeeding problems and my baby got dehydrated. "Get me out of this hospital!"

Eventually I came out eight days later and we could start our lives over again. And that was very traumatic for us. But everything was fine and we got on and everything was really good and then my hormones began to get back in and after six months my periods started again, I got my first period, it was like normal, fairly normal. And then I didn't get another period again. It was like I got ... I was pregnant again. So I was pregnant within seven and a half months of Jessica being born and that was really shocking, really, really shocking. There was lots of fear now that, "Oh, you're going to have to have a caesarean again." I said, "I'm not having a caesarean." They said, "If you want to, you know, because you're having a baby so soon, you have to have a drip put into you through your labour so we can access your veins in case it becomes an emergency." And, of course, that meant they could only do it in my foot or in my groin, which meant I couldn't have an active birth. So this fighting began about three months into the pregnancy and in the end it was just, "Just stop, just stop. I'm going to have a home birth." And it stopped the hospital fighting with me.

And, of course, when my first child was born and I had the caesarean I couldn't bend down to my suitcases and one of the midwives realised and she brought me an extra cradle and put my suitcases into the extra cradle so I didn't have to bend any more. And they put me in the first bed in the ward which meant that everybody entering the ward saw me and did a double take and it was, you know, anybody saying ... sneezing in the presence of a woman who's just had a baby in the second day, they're in for trouble, you know, and it's like, "Get me out." And I had the curtains wrapped round me. It was like, "Oh God, what's going to happen with this second baby?"

And I didn't believe I couldn't love another child as much as you love your first child and all those things we all feel about the first and I went into natural labour with my second child, she stayed head down, and I had a great birth with her and she came out with all her bits and bobs and came out shrieking and yelling and all of that. And the midwife ... I had the same midwife, because I'm lucky in this area, she just put me into a room. She said, "You need three days on your own without your first child here. Have some peace, stay as long as you can, you've got a private room." And it was great because the difficulties in getting dressed

when you've got short arms and you're sweating in a hospital and you've got milk dripping and you've got blood pouring and all the rest of it ...

*You don't want people staring at you.*

No. And I didn't have my comforts at home to help me. And the private room just meant I didn't have to get dressed, you know, I didn't have to get dressed in the room. If people wanted to walk in and see me naked then they would learn to knock very quickly which they all did. And it was much, much easier for me with my second child. Also I was walking around immediately. With the first one I couldn't walk for twenty four hours, she was a caesarean.

And then I came home and life took off, absolutely went mad. My first baby still wasn't walking so I had to carry her everywhere. So I'd carry her and they learned ... they knew that if I was carrying one, I was coming back for the other and it was a very, very interesting experience having two children with a disability, no help. My mum, by now, had emigrated to Israel, was living in Israel. My step mum I don't know why, she didn't come and help me, she just didn't. I think she thinks it's because I didn't ask her but I didn't know how to ask for help. And, as I hadn't had much relationship with her since I was fifteen / sixteen, it didn't occur to me to ask her.

*What about Paul, was he helpful?*

Well, Paul was at work.

*But when he was at home?*

He would come home at five thirty and I was always bathing the children. Throughout the day I was always on my own but he would help me finish the bathing thing, put them to bed. They went to bed at six. I had a very, very specific routine and it was really important to me because it was how I could handle it. If I fed them at four ... if I fed them at half past four they would be screaming and crying and hungry, so why wait for my kids to be screaming, crying and hungry, I can't hold two at once. Feed them before they get hungry. Just make sure their needs are met before they have the need.

And that was how I functioned and I did discover that it didn't take everybody half an hour to change a nappy. I'd say to my girlfriends, "Are you coming?" "Yes, I'm just going to change their nappies, I'll see you in five minutes." And one day I went ... she used to get really mad that I was always late and one day I said, "What do you mean you'll see me in five minutes?" She said, "Mikey, how long does it take you to change a nappy?" And I went, "Well, the two of them, about half an hour." And she went, "Half an hour? What's the matter with you?" And I went, "I don't know, how long does it take you?" I didn't even realise that, you know ... so whilst mothers were going off taking their children to classes and things it was like I couldn't get out the door.

And in the winter it takes ages to get a coat on. So I'd wrap one child up and then I'd wrap the next child up and then I'd wrap me up. And if they needed anything I'd have to unwrap me and then go and get it. So it was like I had to make sure I had everything I needed and then get out the door. And we walked every day, just out in the fresh air because I just couldn't get one into a car seat and another one into a car seat. Plus my older one, before she was two ... no, around the age of two, was wriggling out of her car seat, five point

harness, it just wasn't safe to take her anywhere. She was climbing out of her five point harness in a high chair. I put her in a five point harness in the end. She'd get out of that and just stand on top of the high chair and fall off. It was like, "What are you doing?" A completely mad, wild kid who was just ... you'd put them on a baby swing and give them a gentle swing and it was like, "No! No! No!" Fling them high and they'd scream with pleasure and they'd climb the slides that nobody under the age of three was allowed on and my two year old would be crawling up there, completely out there, loving life. Just being adorable.

My older daughter was so helpful with my younger one when I came home. So Paul would help me again in the evenings but eventually he stopped helping.

*How did that happen? When did that change?*

Jobs. He changed jobs. I can see it now but I couldn't see it then. He changed to the job he's still in now. You know when you're in a relationship and you've got children and you don't sleep properly at night sometimes and it's hard and you forget about each other and both of you have a responsibility to remember the other person. And neither of us knew how to take that responsibility, just like in all other relationships. But he was going to work and I wasn't so I was in it, this was my environment all the time, and he wasn't. And I remember him talking about the secretary or the receptionist one day and making a joke and I would sporadically, once a year, make a comment ... stuff would suddenly come home from her – toys for the children or clothes for the children and I would go, "What have you done to curry your favours there?"

And, of course, then he wouldn't come home early and he started going out drinking and, you know, life just got absolutely awful at one point, we nearly broke up. And I said, "I never want to go through that again. If we're going to do it now, it's got to be proper, we've got to get our way through this." And we just couldn't and he went out drinking ... he's a very, very good drinker, he holds his drink well and he enjoys it. He would do that and then travel to America sometimes. But every morning he always made me a cup of tea in bed and it's certain things he always did because he's a good person. But he just got very misguided and he felt I wasn't nice to him and I felt ... he was never not nice to me. I would never say that he wasn't nice, there was just a complete breakdown in communication and I just got more and more tired, more and more exhausted. And I do remember one day, when he was going off on one of his trips, and his boss always picked him up. And I said, "Where's your boss?" And he said, "Oh, I've got to go and pick the boss up." And I remember thinking, "What?" And I said, "Where does your boss live?" And he said, "Lindfield." And just the way he said it I knew exactly what was going on and I thought, "No way!" Because the receptionist / bookkeeper was called Linda. And I just thought, "No, this is ridiculous, just stop it, I've met her. Don't be silly." And I remember one night sitting up in bed and thinking, "Oh my God, he's having a relationship" and lying down again. It was like, when would he have the time?

[Doorbell rings]

Can you go round the back? No, I'll just carry on before they come in.

So when he told me one day that he was going to leave, I just said, "Time will tell why."

[Doorbell rings]

It's not, you have to bang the handle. It's not. Get the key; I'm interviewing, get the key.

And yes, and of course he's now living with Linda and has lived with her for four years.

*And how long was it going on for that he was seeing her?*

He will never own up to that. I have no idea if he really was. But there was something going on. She probably gave him the strength to leave, to find the courage to leave his family. But we were going nowhere. We'd hit a dead end and if there was going to be no growing we were at the end of it and he just wouldn't come and see a therapist with me. And I spent years trying to find remedies for feeling sick all the time and feeling angry and depressed and, of course, as soon as he was gone the sickness went, the depression went. It was just the stress and the unhappiness of living with someone who was living a lie.

[Interruption in recording].

*So we were just talking about the end of your marriage.*

Yes. I don't know whether he was actually seeing her at the time but I think her presence was an invite to him ... she's very much like him, well actually she's not. She is what he thinks is the right way to be. Does that make sense?

*She fits his idea?*

Yes. His current idea. And if he's happy, that's great. She welcomes the children into her home, which is wonderful. Jessica is very happy in her home, Maddie, who's the younger one, is not happy in the home, doesn't like her children who are much older and makes it very clear she's not happy. And because she makes it clear she's not happy, they're not happy and then, you know, and so it goes round and round. And she quite rightly says, "If my dad wants to see me, he can come and see me in my home. Why should I give up my weekends to go and visit him?" So we have this whole dynamic and it shifts the family around. He won't take any responsibility for it. He just says, "When she learns to behave herself ..." and it's like, "Don't you understand, this is a child in trauma?" And he can't see it. But the fact that he can't see his child in trauma is an example of how our relationship became in the end. So much trauma and stuff.

So, yes, that's where he is. He doesn't live with us, he lives with another woman. He has his own home; he has a mortgage with her which he never had with me. He was never prepared to invest in the home financially for some reason.

*Did he always continue to live in what was your home?*

Yes, he had his own house and it's very interesting because there was money coming in from the Trust and it wasn't enough to do the things that I needed but when you add it onto an average salary it suddenly like doubles it ... not doubles it, it adds another half of the value. From going on the bare minimum, you're suddenly becoming comfortable, you put the money together. And I think ... he's not the only one, if you've got a mortgage on a home, you're saving the family somewhere between seven hundred and fifteen hundred pounds a month. And, to me, that's my input, you know. The fact that we don't have the mortgage is because I've paid it off already.

So this whole thing of ... when the woman doesn't work and the man works, the theory is that the woman's not putting anything into the home. She's just bringing up the children and not being paid for it and doing all

of that. And I never expected that but I did feel the need for an acknowledgement of ... no, I didn't feel the need to be acknowledged for the fact we didn't have a mortgage, what I wanted to stop happening was to stop always being told I wasn't allowed to spend any money. The only money I was ever spending was on the children. So we had this feeling always going on. So I always bought my own clothes, I never used his money to buy my clothes, it was just ... I never had, I always bought my own stuff and why would I change that? And maybe I should have. I don't know, but I didn't. And with him gone I don't feel like he took my money but I just know he can never, ever say that I took his [laughs].

*Well, that's something, isn't it?*

Yes, yes.

*Does he provide support for the children?*

Financial support?

*Yes, like maintenance.*

Yes, because we weren't married he doesn't pay me maintenance, which is a very interesting one to swallow and get through because if we were married and you think that you give up ... at this stage it was nine years of your life, you have children. And it's very, very hard for a woman. You come out of the workplace ... to get back into the workplace, it's just ... I went from being a thirty six year old well-paid woman to, nine years later, a forty six year old woman who's disabled and who had been out of the workplace so long. It's hard and also I had had an accident.

So ... I can't remember the question ...

*About the payment of maintenance.*

So he doesn't pay me maintenance for my upkeep but he gives me money for the children. Now, there's a really bad system in this country, it's the CSA, the amounts of money men are expected to pay ... it's just ... they get tortured and slaughtered on one end, they lose everything and they then have to pay for the children. What is that about? What's happened for me is Paul pays more than the CSA would ask for but he doesn't give me anything. He doesn't give me anything. Well, I say that but he comes to the house and puts the TV up on the wall so there are things that he's done.

He doesn't have parental responsibility because we weren't married when we had the children. All he has to do is sign a form but he won't, he just hasn't done it which means ... both my children have Australian citizenship so I can go and take them to Australia to live and he can't stop me because he hasn't taken that responsibility. And it feels ... well, it's just a piece of paper but marriage is just a piece of paper, marriage is a commitment, parental responsibility is a commitment. And when you don't have that commitment, there's something ... this invisible thing that doesn't tie you together any more and it brings back that whole time of when my father died. The one person that was mine, belonged to me, and I was out on the rough sea whereas now I feel I'm out on the rough sea and I've got two children I have to look after.



So the family thing becomes very difficult. It's like his mother never comes round and it didn't help quite soon after Paul left ... his father got cancer, he got ill then it turned into cancer and after two years he died. So I was out of that loop, there was never a point that I could comfortably go. And now it's four years so nobody thinks they should offer support and that whole side of the family never, ever think that their grandchildren will only be fine if I'm fine. The most important thing in these children's lives is me and none of them make sure that I'm okay. So I just step away from it, the children see their dad and they see their nanny if their dad takes them. Or she calls or wants them to do anything but it's very, very rare.

So it's quite difficult because I feel like I've lost another family like I lost my dad and I lost Paul. But I couldn't carry on living with him, it was just not going to happen. It couldn't have done without destroying me and the children in the process and it's a shame because he was a good bloke. And the minute I set eyes on him I knew I wanted to have children with him and I told him that and I told him I wanted to have two children. Actually I wanted to have three but I always thought three was a treat and he actually said once Maddie was born, he said, "You don't need me any more, do you?" And it was like, "Not really. I've got what I wanted." But I didn't mean that.

*I know what you mean.*

*Mikey we'll have to stop there today because of time but it's been brilliant to hear what you've said. There are a few questions we haven't covered yet from the first part but not all that much. I'd like to ask more questions about the children and bring things up to date but if you don't mind I'll ask you that on the follow up.*

Yes, and I'd love to tell you because of the children's experience of having a disabled mother.

*We keep thinking we need to do a project not only with living parents but also with children.*

Absolutely. Absolutely!

**END OF RECORDING**