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 22 November 2012 at her home in Forest Row for Thalidomide: An Oral History. This is our follow up interview – Mikey did you receive the transcript of the first interview?

Yes, I received the transcript.

And did you have anything in particular that you'd like to comment on from it or raise yourself?

I found it really emotive, reading that, I couldn't believe it was my life story. Yes and there were some things that I thought were really poignant that I'd like to pull out and use as my own quotes even though they are my own quotes. I'd like to use them.

Well that's part of the agreement, you can do whatever you want with the interview, you can use it as the basis of anything you like basically.

There were some name spellings wrong in there and at one point you referred to me in brackets as MK ...

I picked up on that later, I looked through it ...

It always happens, people use my initials as MK. I don't know why.

It's because it's Mikey, it's the syllable thing. Yes, I picked up on that because I read it again when I was thinking about today so I picked up on that as well.

We got to the end of the last interview and we were talking about children and the breakdown of your marriage and you mentioned there were a few more things you'd like to say about your children, things like how it's been for your children growing up having a mother with a disability and a single mother with a disability.

Yes.

I don't know if there's anything you'd like to say about from their point of view?

Yes. I'd love to. Jessica's my older child and she never questioned or asked anything until she turned three. And I didn't know that three was a magic age for becoming aware of disability and we were sitting in bed and she looked at her hand and she looked at mine and she started turning her hand over and she started going, [chants] "Mummy's hand is different than Jessica's, Mummy's hand is different than Jessica's." And I sort of said, "Yes it is" and we had a look and I don't remember the whole process. But a few days later we were at a mother and toddler group that we went to once a week and a child, who also had just turned three, asked me a question about my arms and the ... unfortunately the woman running the group got embarrassed and came along and told this child it was something to do with the angels and took the child away. And Jessica just sat there and her face fell, her face had fallen. And she just kept looking down and she ... just these tears started to fall out of her face and after that, for three or four months, whenever I tried to raise the subject with her, her face would just fall into this like ... there was this shock and horror and surprise and sadness that her mum was different.

And it passed because I showed her ... I said, "Oh, having something different isn't bad, it doesn't mean you have to feel sorry for me. I can still hold you, I can still cuddle you, it's made no difference to how we are." And the interesting thing is her little sister, who's only sixteen months younger, so she would have been a year and twenty months or something, at the time, was watching everything really, really like watching it because she knew something was going on, some trauma, some emotional thing. So by the time she was two and a half she was actually aware that my arms were different and she'd sort of pick up my arms and look at them, like suddenly they were different. But she knew that they were different. And so she didn't have the shocking change.

And the children do talk about it. They see people stare at me, they take no notice of people staring at me – sometimes they do, sometimes they don't and their friends always ask. And, in fact, one day Jessica brought home a friend from secondary school in year 7 and ... gorgeous girl, really lovely girl, and then she came round two or three times and then suddenly she went, "Oh my God! Your mum's arms!" She hadn't noticed. She just hadn't seen them.

So my kids just thought that was hysterical. How can they not see them? They don't see them but how could you not see them? And children ask them all the time and they just say, "Oh, she was born like that." And they just leave it at that because they see that ... I say to other children, "I was just born like that" and I don't fight people about it.

Have ever people spoken to them about thalidomide at school? Is that something that's come up in the curriculum or that they've been asked to discuss?

It has come up in the curriculum on a ... I don't know. All classes are called different things these days. Religion is not called religion any more, it's called beliefs and values and then they do something called personal development. I don't actually know what they do in personal development but the teacher on the day Jessica wasn't there chose to discuss thalidomide. That's what he had on the curriculum, she happened not to be in that day but he continued with it anyway.

How silly.

I actually think he did it that day with Jessica not there because I think he was embarrassed. Even though he spoke to me and said, "Oh, I was thinking of Jessica that day because we spoke about thalidomide" and I thought, "Oh, you scaredy cat," you know.

That would have been a great moment for her to be able to, you know, speak out about what she knows, wouldn't it?

Yes, it would have been a great moment for her to shine. She shines anyway at school particularly. She's top of the class in most things anyway. It would have been another thing for her, but it would have been great because it would have made her feel very proud. But Jessica has always been proud of me, she's deeply proud of me and she's never had any embarrassment about having a mother, let alone a mother

with a disability. I mean that's just not part of Jessica's worry. Maddie, on the other hand, has always been ashamed that she has a mother because it means that at some point she came out of me so I [whispers] must have had sex. So it's that whole thing ... you know, this whole torture that goes through a child's mind. When Maddie was in year 6 I was banned from coming into the school but it was nothing to do with my disability.

When the children were very little, when Jessica went to reception, none of the children asked me any questions, I was never clustered around at school, nothing. The following year Maddie went into reception and it was a whole different story. The kids gathered round me in the playground, all her year group, they asked me questions, "What happened to your arms? Why are your arms like that?" And because that happened, I spoke to the class teacher and I said, "Would you like me to run an assembly?" And he said, "Oh Mikey, we'd love you to." So I went into this assembly and they say you only give them the amount of minutes for their age. So the average aged child was between four and six so I gave them five minutes of talking and on the way in I took a stone and an acorn ... an acorn leaf and a stick. It was representing all the different sizes you are as a foetus before the drug hit. So I showed them a picture, so what I basically said to the children was, "I've come to talk to you about my arms." This goes straight in and, "I want to tell you about why my arms are like they are because I'm sure lots of you are interested." I said, "Did you know when I was a little girl that I had short arms?" "Gasp." "Actually when I was a baby I had short arms." "Gasp." "Actually when I was in my mother's womb I had short arms." "But actually when I first started in my mother's womb I didn't. Let me show you." And the kids couldn't believe I had short arms as a baby as well, you know, they just couldn't see it.

When I went into that assembly, Jessica was so proud that her mum was speaking, she just came and sat right next to me and Maddie sat in the back and just hid in deep shame, even though reception children sit in the front row. Her head was just turned away from me, from anybody, and slowly, but surely, when it came to the children that were asking questions I noticed that she kind of somehow had shuffled her way forwards and by nearly the end of the assembly, she was sitting in the front with me and her sister proudly looking around. "You ask my mum questions." The kind of questions the kids asked were, "How do you put your shoes on?" And I said, "Oh, like this, because I had slip on shoes."

Yes, I think when my daughter first came across thalidomide affected people, she asked very simple questions, very practical questions like, "How does …" meeting somebody like Louise, "How does she brush her hair?" The things that matter to her, like she wants to brush her hair.

Yes, yes, yes! Well I think Martin Johnson told me a story ... I think he'd met ... he was doing his rounds at the very beginning and he was just ... he met somebody and he said, "How on earth do you brush your teeth?" And they said, "With a toothbrush" [laughs]. And it was like, "That told you."

Exactly. I can't imagine Martin saying that actually.

No, I know.

But I suppose when it's all new, yes.

Okay, now there's two questions that are perhaps a little bit more upsetting and if you don't want to go into them that's fine. One thing that really struck me in your other interview when you talked about your mother

attempting to abort you when you were pregnant, you did talk about that in quite an upbeat manner. And I wondered who it was who told you that story? Who told you about that and if you could say a bit more about how that makes you feel.

My mum told me. And my mum tells me things sometimes in a very disconnected way. So when I got to know my mum when I was fifteen and began to grow a bit of a relationship with her, she would tell me stories about things she used to do and things she currently does with her three children. And I'd look at her and I'd think, "Well, I haven't done that with you and I'm one of your three children" and I noticed that my mother was just that kind of person who told stories. They might be true but she told them as a story so when she then told me ... when she told me, when I asked her, "What was it like mum?" she told me a story that ... she has probably told the story but doesn't make the connection to her or to me. So when she told me, "Oh yes, well of course I tried to get rid of you" it's like well of course anybody would try to get rid of their child if they discover they've taken a pill that might damage their child, of course anybody would, you know. "And then I tried to abort you the second time," you know, it's just that's just my mother and it's really only, particularly this last year ... my mother was interviewed two or three years ago on that Days of Our Lives, or whatever that programme was called, and she broke down on the interview and she was crying. And I've never heard her break down and cry about it. And it was like, "Wow." Of course my mum's got emotions and feelings about it but it was like she's now stopping telling the story, she's now feeling the story and so that interview had really brought her out and I was actually more gobsmacked that this story that I'd been fostered out appeared and then I thought, "Is it just another one of her stories?" I don't know.

But certainly in the last year I've done ... I mean I've done therapy on and off over the years and I never find therapy successful because I somehow manage to avoid anything that's really painful to talk about and the therapist never seems to have the courage to make me talk about those things that are really painful. But I know a woman called Natalie Lamb and she would say ... she's a friend and she's probably one of the best therapists in the world ever. And I would say something like ... I said to her one day ... I'd watched a neighbour of mine, they're a couple and he had cared for his wife and she wasn't interested in him caring for her and she was ill but she was recovering and we were sitting chatting. She was absolutely, absolutely fine and he walks in and she became a wreck, unable to function, and he said, "Oh darling, let me carry you up the stairs." And he picks her up and carries her up the stairs and I turned round to my friend Natalie and I went, "It was disgusting, it made me want to put my finger down my throat and hurl, you know, it was just ... she was using him and he was ... he's so namby-pamby, what's the matter with him?" Right? And she turned round to me and she said, "Oh, Mikey, that's your experience of it because you've never been truly loved. You don't know what it's like when somebody truly loves somebody else and wants to look after them. And my mouth fell open and then I thought, "Oh God, she's right."

So the fact that I'd always thought of this man as namby-pamby ... this was about two or three years ago, I just thought, "Perhaps he's not." And next time I saw him it was not in my judgmental way of nancy man who just keeps being weak and feeble and, "Hey darling, how are you?" And look at it as a love thing and I can see now what a wonderful man he is and he's become a really good friend of mine. So she has ... I haven't really been loved, well my dad really loved me but he died young and I ended up ... I've got this situation. And so the therapy is like ... I can't remember what I said but I said something to her about rejection because I often think I don't have friends, people don't like me, people don't want me around. And, of course, she said, "Well, of course you feel like that, Mikey. Your first conscious experience, as an unborn baby, was rejection. Your mother didn't even know you were there, the minute she knew you were there she didn't want you." I was, like, "Oh ... okay." Now how can I live with that?

So we did quite a lot of therapy on that so when I told you the story it was ... I was telling you the story, I guess, in the way my mum always told me and how I've always looked at it and how I've always separated my thalidomide disability from Mikey, in a way. But ... I can't remember what I was going to say now ... but I

realised that a lot of the way I behave and a lot of my ... my unconscious starting point comes from the fact that I was rejected at the beginning and all the way through my ... through her pregnancy with me.

So I see it in two different ways. Now she knows me she wouldn't reject me, it's not that she's rejecting me. And it's just like in the world when I go out and people look at me in the street and they don't want to talk to me or they don't want to give me a job. It's not because they've seen Mikey, they've seen short arms and they're afraid and they run from that.

And it was guite interesting ... I had an interesting experience in Israel just the other day because I really didn't want to leave Israel ... I wanted to see my children but I didn't want to leave Israel. I have this big issue when I have to leave Israel and I wanted to live there in the eighties and it was too hard for me, it was really hard as a disabled person to live in Israel. It's very different now but then there was just no acceptance, there was no ... they still talk about it. The guys who have been injured, it's a different story to the people with a disability and it's like you see the disability and you think that's the person whereas somebody that's been injured, you remember that they were a normal person so you pretend the disability is not there but you still see the normal person but you can't do that with a disability. My Israeli friend couldn't understand what I was saying because he's never challenged his thought and my mum said something to me as well that's quite interesting. She was really rude about a disabled person in the street. I've made jokes in the past, you know, funny comments ... oh, another disabled person, oh, hipply cripply or whatever. I don't speak like that any more because it's about ... when you have those thoughts, thoughts become things and if you think like that about someone then someone else can think like that about you. So I said to my mum, "Don't think like that" and so she laughed and made another joke. I said, "Actually mum, that's racism and it's discrimination." She said, "Well, you know I'm not racist and you know I'm not discriminating." I said, "Yes, but you're speaking like you're discriminating." And she got really flustered because it's about taking responsibility for who you are and how you think and I said, "Yes but that's what you're doing." And she said, "Well, I'm in Israel, I'm just doing as they all do here." And that's her perception of what they're doing there and I just said to her, "You know mum, we need to change the world and you have to be the change, change can only come about by each individual taking responsibility so you need to be the change. You need to be the change we want to see in the world." Then I got on a bus and the bus drove off.

So in answer to that question, it's still having repercussions in understanding what she said, believing that it hasn't actually affected me because I'm separate and then discovering that I'm not separate, that I am all those things, that I am a person with short arms and that makes no difference to who I am.

Yes, yes. So it's integrating all those different parts of you from rejection in the womb right the way through to how you've learned to live your own life and tell your own stories and fitting it all together.

Yes and like I talked earlier in the other interview about living consciously, how I'd lived most of my life unconsciously, like most people do, we just get through and then suddenly I was, like, I've got to be conscious about what I do. I'd never pulled my mother to task on things like that. I've asked her not to be cruel to my husband when she's having a go at him or, you know, I've stood up to her but actually that was quite a defining moment which was spoiled by the fact that when we got back to the apartment in the afternoon there was a bomb scare and we had to ... we got distracted by bombs dropping and everything.

Thank you for that answer to my question. The other sad time I wanted to talk to you about was your father's death and you talked about being there when he was actually dying and I wondered what impact that had had on you given that you were so close to him and, again, you talked about that in a slightly detached way ...

Did I [laughs]?

... which I understand but I wondered if you could say a little bit more about that, what happened during that process of his death and immediately afterwards for you?

Yes. What he actually did was he fell on the floor, he just collapsed down on the floor and my dad was an actor and he had cried wolf about three weeks earlier. We were out walking and he hurt his little finger or something, my stepmum booted him with a playful kick and he put his hand out to pretend he'd hurt his finger so he rolled on the ground, rolling on the grass, aaaggghhh ... aaaaggghhhh. And she said something like, "You shouldn't do that, you shouldn't cry wolf, no one will believe you next time." So when he plonked himself ... he suddenly fell down on the floor this was ridiculous, it was like here we go again and I couldn't lift his head and I remember trying to lift his head because he was face down. So either I rolled him over, I can't remember that I did, but he was on his back. I can't remember the details but I began to get afraid because he wasn't responding to me.

And I called out downstairs to my stepmum's mother who was there because it was the night before she was coming home with the baby and she shut the door, I think she just wasn't interested. I just went into absolute terror. So I went across to a neighbour, I said, "Something's really wrong with Dad, can you help me call the doctor." I didn't know how to call a doctor, I was fifteen, I know this stuff. And the doctor came round and, you know, declared my dad dead and it was devastating. I think I've only ever properly collapsed twice in my life and that was the first time. I was at the bottom of the stairs and the doctor walked across the landing and he stopped at the top of the stairs and I can still see him in my mind and he just stopped and he looked up and I was like, "Is Dad all right?" And he hesitated and he just said, "No." And I think he must have flown down the stairs, I've no idea, and I remember screaming and then being picked up off the floor. And it was shocking, absolutely shocking and I always want to make things right, make things better. One of the things I'm learning in life is not to try to make things better for people, not make things worse for people but not to fix things. My first thought was, "We've got to find another man for my stepmum before she comes home so she doesn't notice that my dad's gone." So my first concern was for my stepmum and then all that pain, "Oh God, I'm not going to see him again."

And I think, you know, when somebody dies you have that pain of never going to see them again and it comes in real big waves and I remember being so afraid to sleep that night. So Ida, her name's Ida, my stepmum's mother, slept on the floor in my bedroom and she was in her sixties. And then we brought my stepmum home the next day and I had to tell my sister, my big sister, she was living in Australia. And by chance she phoned ... I don't know if I've told you this bit, have I?

I don't think you have actually.

My big sister phoned and I answered the phone. We tried to phone my mum that night, in London, but all lines to London were engaged, as they were in those days, you know, you had to dial 01 or whatever. We hadn't got through to mum and then we'd gone to bed and then my sister phoned and I said, "Listen Claudette ..." She said, "Can I speak to Dad? I must speak to Dad." I said, "Look Claudette, I'm going to tell you something and then I'm going to hang the phone up on you and then you'll have to wait about ten minutes and then mum will call you." She said, "Get off the phone, I just want to talk to Dad. Bugger off! Let me speak to him and just stop annoying me." I said, "Listen Claudette I'm going to tell you something and I don't want you to run away, I want you to hear it. Then I'm going to put the phone down on you, I'm not going to talk to you afterwards. I'm going to put the phone down when I've told you

and then Mum will call you but you'll have to wait for her call." She said, "Urgh, for God sakes, hurry up." I said, "Okay, Dad died last night." And I heard the scream, I just put the phone down and I thought, "I don't know what to do." What do you do?

So then we phoned London and we got through to my mum and my mum had a very interesting reaction. First of all, she thought I was having a bad dream. I said, "Mum, Dad died last night." She said, "Mikey, have you had a bad dream?" No Mum, Dad died last night" and there was silence and then she said, "Why didn't anyone phone me last night" so instantly we were in the wrong. And I said, "Well, we tried to but all the lines to London were engaged." And there was silence on the other end and my mother has these very fierce silences if you can imagine that. It's like ... when my mother goes silent it's like I've done something wrong. So there was always that feeling that I'd done something wrong and then I went, "Mum, Claudette just phoned and asked to speak to Dad and I just had to tell her that Dad's died but I said that you would call her so can you please phone her now?" And there was like this silence on the end of the phone and obviously my mum was in shock. I asked her to put the phone down.

I do remember my mum saying to me a while later, she said nobody thought of telling her, even though he was no longer her husband, he'd lived with her all these years and nobody had cared about her and I just thought, "Oh my God, you're the only person we cared about. We wanted you as your children, we wanted you as our mother and we wanted you to know because you were married to him. You were the only person we cared about and we couldn't get hold of you and now all you're doing is complaining." And I've never said that to her, I've just never gone back and re-visited that with her and then ...

How did your stepmother take it?

Well the police, she was woken in the night by the police and, I think, a midwife. I think they woke her ... by the time the police got there it was about two o'clock in the morning. She just went hysterical but they told her that there'd been a bit of a scramble in the house, a bit of a fight, so she blamed my brother for a long time and my brother was really damaged by it. I mean my brother was damaged anyway by whatever. Damaged goods is horrible but he was just so emotionally unbalanced and then that just freaked him out. My brother and I have never talked about it. He was like, "I didn't kill him, I didn't kill him" and I said, "No." "I didn't push him." I know he didn't push him. It was the big fight and, you know, the stress of it was just the final straw for my father's heart. If you're going to have a heart attack it's going to happen whether you're having a fight with someone or not. It could have happened behind the wheel of a car. He could have saved our baby's life by ... you know.

So there's no detachment in it. I can tell the story but there's certainly night upon nights I can lie in bed crying even now because I miss him.

Was there any signs beforehand that he had any problems with his heart?

Occasionally he'd have pain in his arm and because I was born in Australia there's the Aboriginal connection ... you know, I'm not Australian and I'm not an Aboriginal but the Aboriginals were known ... there was a group of them who experienced the birth pains of their pregnant partner so we just called him the Aboriginal because he was having ...

Pains in his arm.

Pains in his arm. It was happening in his arm instead of his belly or maybe that was just my thoughts. I don't know. But I do remember him complaining about it and I do remember making a joke about Aboriginals but no, he didn't go and get his heart checked. But a month before he died he took out a life insurance policy, a life insurance premium, we're very thankful that he did that because he paid one premium and then it had to pay out. But he was able to take that policy out without a medical check up and had he had a medical check up, we may have discovered he had angina and he could have been on the drugs immediately. Then he may not have had the heart attack and it may not have happened but when it did happen there was the money, so I don't know. But thankfully, something came out of it, if you know what I mean. It gave my stepmother a bit of financial assistance.

But, again, I remember walking ... finally going to school ... I didn't go to school for three days and then I went to school. I think two or three days and then I walked into ... right outside our classroom there were these pegs and we were right next to the teacher's room because we were the oldest class in that building so they probably thought they needed to have us close to them to watch and I would always hang my coat up and walk into the classroom. And I wasn't one of the cool kids, most people didn't say hello to me except my friends. Everybody stopped and said hello to me so I knew they knew something and that was really, really nice.

But I remember walking home and a neighbour actually saying to me ... she stopped me in the street and she said, "You know, Mikey, it's very, very sad you've lost your father, it's very, very sad but you must understand it's much, much worse to lose a husband so you must understand the situation is much, much worse for your stepmother." And I remember ... I mean I still can't find peace with that woman today I must say and that woman now has ... I don't know if it's Alzheimer's or dementia and, funnily enough, my stepmum helps to look after. But I can't give her that space in my heart yet, I just can't give it to her because that was so damaging. I remember feeling so unrecognised and so hurt.

Yes. Why would anyone say that to you at that moment in your life? And who's to say who's more hurt by anything anyway? I mean ...

Well, it's funny because this friend of mine, Natalie, who's this therapist, I did raise this with her and she knows this woman and she's very aware that this woman's life centred around her husband. So, for this woman to lose her husband would be the worst thing in the world but I didn't make that connection, you know, I was fifteen years old and I wasn't ready to hear stuff like that and that was very hard, it did change a lot of feelings, I had a lot of guilt. When I wanted to cry I would stuff it inside. I can because she's just a liar ... it just made me feel nobody cared.

Or that it wasn't fair for you to ask for help because it would be being selfish if you did.

Yes. And here was this woman with a newborn baby. But, interestingly, in life now, nothing I do is ever as bad as her being a widow with a newborn baby. It still comes up and I did the first year of a degree with the Open University and I had to go to University for a week and in that week, just before I went, I discovered I was pregnant with Jessica and I was already starting to feel a bit sick and I remember I was in a science class and I had stepped outside and I was sitting in the sun trying not to feel sick and a woman came and started talking to me and she was some form of therapist like a psychiatrist or something. And I had no idea why she started talking to me about what she did but she ... all I remember her saying to me is that women have three greatest fantasies and one of them was losing your husband when you've had a baby. It was the number one fantasy of a type of woman who is always looking for attention and who feels insecure. I can't

remember all the details and I went, "Oh my God," I said, "That's what happened to my stepmum." And she said to me something along the lines of, "It's interesting how your stepmother was to create that ... to make that fantasy come true."

And, again, it's that whole thing about thoughts become things and it's really scary if you think, "I'm going to die of cancer." Am I going to die of cancer. But it wasn't about that, it was just about creating the life that gives her the attention that she needed. And, as I said earlier, she wasn't the priority in my father's life, us three children were and then my mother fitted in somewhere in that. And I was very aware of that even then because as a youngster I was quite spiritual but I didn't really know that I was spiritual. I just understood things and, as they years went by, I lost those things because as I tried to talk about things people just thought I was crazy. So it kind of just drifted away but now it's coming back. I seemed to maturely understand things then but then I lost sight of as I grew up with all the struggles and all the different things that went on, that I'm beginning to re-find. Does that make sense?

Yes, yes. Completely. Yes. Okay, now we ended up at the point of your marriage break up and I wondered if you'd been seeking other relationships since then. New men?

No, not really. One of the things I discovered was that I never had the courage to talk truly about my feelings. It was kind of like if two people like each other you just kind of look at each other and you don't say it because you just don't say it, do you? But why don't you say it? So something happened with somebody that was a massive misunderstanding. I just thought we were hanging out, that person thought that I wanted more. I didn't know how to explain that I didn't want more because I thought it was embarrassing. Anyhow, a few months later I met someone and they actually started talking about their feelings for me and I couldn't believe it. There was kinds of hints and promises of ... and it was wonderful, absolutely wonderful and I have to say that I ... let's put it this way, if that person had said, "Let's go and get married now" I'd have gone straight to the church and done it even though I'm not Christian. And yet we barely knew each other. It was barely ... three weeks on and off, phonecalls, connections.

We met in London. By chance the man lived locally in Tunbridge Wells. Anyway he said to me he couldn't do it. I made him ... it's quite funny actually, I believed everything he said. He said that I made him confused, he knew exactly where his life was going but around me he didn't know where his life was going and so on and so forth, blah, blah, blah, blah. And he didn't want to see me any more and that was fine. And I sort of got over that. I was very sorry and occasionally he would say something to me and I felt he was a tiny bit patronising about my disability but I thought we'll get over that.

Anyway I was walking home one day on a road parallel to where I live, over there, two hundred metres as the crow flies, if that, and there was this car parked outside. "What's your car doing in Forest Row?" Anyway, to cut a long story short he'd been seeing a woman for over a year, she'd got two kids, the whole thing ... he didn't want to be involved with me because she'd got two kids. It was all bullshit, all a load of nonsense and the shock ... I actually can still feel the shock as it went through my body, my whole body jarred, it's like a part of me separated and the raging, angry part of me became the existing person and I just searched and searched for answers. And I just couldn't find this calmness that I had been before I saw his car.

And I've never had fights like that with anybody but I went round to his house and we had a fantastic fight, expressing real feelings and really shocking that I could talk like that with somebody because with Paul, my ex, you know, it was always ... it just didn't happen like that, there just wasn't that maturity between the two of us and the thing is that I felt so powerfully about this man ... I mean I actually saw him quite recently by chance. And I thought I hadn't seen him in ages, I'm absolutely fine ... I mean I spent three years being hurt. I couldn't get over the hurt. I missed him for the first two years. I missed his body, I missed his touch,

everything. And I was so angry and slowly but surely I began to realise with jolts that everything he said to me wasn't true or probably wasn't true.

When I saw him, it was only two or three weeks ago, he was hinting again at stuff, how real it was, and I just thought, you know, I'm not understanding something, I'm just not understanding something. I know this man's a player but the reason I actually went to see him was because we think people hurt us in life ... people do things and they hurt us and we go, "Oh, that person hurt me." And then you discover that somebody says, "Oh, Mikey hurt me." And you go, "I didn't hurt you, did I hurt you?" and that perception of our interaction has hurt them. A girlfriend said to me that I'd intentionally hurt her repeatedly two years ago and that's why she won't forgive me. And it's like, "What have I done?" "Well, if you don't know what you've done ..." "No, I really don't know what I've done. Really, really." She won't believe me and now we have this peculiar friendship where it's based on the fact that I hurt her and she's got this grudge but she's going to be my friend anyway. And I can't deal with that.

Especially if you don't even know what you ever did.

No, I really don't know what I did and I was so hurt to think that she thought I would even hurt her intentionally and again this is where the word conscious living has come really strongly to me because it's like, hang on, if she really believes I've intentionally hurt her perhaps these people who I gripe have hurt me, have no idea. Perhaps this man really has no idea how I felt and how he hurt me because it's just something that he does and he doesn't realise how hurtful he is. So I took the courage of going to see him.

It's possible, you know.

Yes. That's what I thought. And I went to see him and he said some stuff and he started to say some stuff and I thought, "You're doing the magic again, mate, and I'm okay with you but I think I now need to go and I'm going to be fine when I go to the mobile phone shop." By the next morning I wasn't fine. "Why aren't I fine? I don't want this man to touch me. I don't want to have that physical relationship but I'm not fine again about him." And it's like, it's like ... what has prevented me from meeting other people? Because there are other people who have occasionally fancied me and I don't fancy them because I don't that feeling that I got around that man; I don't feel that way and even though the man is a liar and a cheat because he had a girlfriend and I didn't know he had a girlfriend because I have a motto, I don't sleep with other people's husbands and I don't sleep with other people's girlfriends and I don't go and sleep with a man who's just left his wife and who's just left his girlfriend because I don't want to be a one night stand. I do fall in love with people who I have sex with. I don't have sex with somebody I don't fancy. I'm not that ... I wish I was. I wish I could just go and have sex fifteen times with fifteen people and so I've forgotten who number three is, let alone number one or number two. But I can't. I have to somehow work stuff out differently.

You want an emotional bond with them of some sort.

Yes. And that's the only way I can get into bed with somebody. And so I felt so disrespected and I've had to sort of work that out and I also know that with Paul leaving it was going to take time. It's like with grief, sometimes you just have to do the time. Whatever you do in between, whatever you do in that time is up to you but time just heals things and I think I'm healing.

So I actually noticed quite recently that I wasn't on the lookout for people and then rejecting them because, you know, I'd be on the lookout for people and they'd reject me and I'd think, "Why aren't they interested?" I've just begun to reintegrate myself back with the children in the last year, give them the attention span, do all those things, get into bed at night and don't even notice that the bed is empty. And I've become one of those women that I never wanted to become that's like happy with myself and happy being single. I don't want to be happy being single, I want to be happy being with a man! [Laughs].

It's probably a good place to be in to meet somebody in a way, to be happy with yourself, because people are very attracted to that, aren't they?

Well they are, that's right. But then it's like I'm not just the average person who just wants to meet the average man. I don't want to meet a wealthy man, I want to meet a man who doesn't need my money, you know? And who doesn't go, "I just want to go to Majorca on holiday." I want an educated man. And I put out a request, it's so funny, I was in Israel and I might have even put the request out before I went to Israel. I said to a girlfriend, "I would like to meet an Israeli man." The thing is with Israeli men, they've got different kind of ... is that okay?

Yes, it's fine, I just check it every now and then to make sure it's all the right ... you keep going.

An Israeli man who's got family in Israel but he lives in England and his English is so good that I can have a conversation with him without thinking he doesn't understand the nuances. He understands everything. This is the dream, this is the ideal ... he's got money, he's got his own house, he's got children, they've grown up ... actually I think I said I'd like ... it would be really great if he had kids the same age as mine. I can't remember if I even mentioned kids. But he really likes me and he thinks I'm absolutely great, he doesn't have any problems with my arms and I fancy him too! [Laughs].

[Laughs]. Not much to ask then!

Not much to ask. And I need him to be Jewish because, you know, non-Jewish men are absolutely great, there's lovely lots of non-Jewish men there but they all keep telling me that I'm too much this and I need to be more of that and Jewish men don't tell me that, they just get it. And Nick Dobrik obviously he says those things to me like, "Mikey, you need a Jewish man." And it's like, "Nick, why?" And he goes, "I can't believe you've had no Jewish up-bringing." He said, "I could put you in Golder's Green and you would fit in so perfectly." He said, "The reason we get on is that you're like every other Jewish woman I've ever known." It's obviously genetic.

[Break in audio 13:13]

I'm sitting on the plane and we've got a space between me and the woman and we're having a laugh and she's sixty-something / seventy-something and suddenly this bloke across the aisle leans forward and gives me a little wave, "hello," and then I carry on talking. Anyway the three of us all ended up talking and he took my number and he was a fast mover. He tried to kiss me on the plane and I think I actually said he's got to be well and truly past his ex, this man broke up ten years ago, divorced his wife, in fact his wife ... his exwife actually died two months ago, she got MS four years ago and the complications ... she died and he's got a son and a daughter, they live in Israel, he lives in London. And I'm not looking, actually I'm not looking to have a relationship with him, I'm not saying he's going to be my potential husband. But the older lady

made a joke and she said something like ... oh, he does something with satellites and she said, "Oh, I must take your number." And I said, "God, you're a fast mover!" And it was that kind of level and he and I were talking about getting married, where I would get married and I was going, "Yes, I'm your wife. I came on the plane as Miss Argy and now I'm going to be Mrs Isaacs" and it was like we were upfront.

What was great, he said to me, "What happened to your hands?" I said, "Thalidomide." And, of course, he's not heard of thalidomide because they don't have ... well, I don't think they've got thalidomiders in Israel but he's not picked up on it on the news or anything and I think, because he's older than thalidomide age, and he wouldn't have being brought up in Israel as a child, and his children are nineteen and twenty-something. So there's a group of people who don't know about it. So he said really rude things like ... he said, he held his hand out and he said, "Squeeze my hand, squeeze my arm." And I said, "I know what you just want to know. I'm not going to squeeze your arm." So we started laughing and I said, "You'll have to get to know me a lot better if you want to know that kind of thing." So he said, "How do I hold your hand?" And we walked off the aeroplane hand in hand [laughs].

How odd.

We walked through the passport ... we broke hands through passport control and then the old lady ... she wasn't that old but she had a stick, she'd done her knees in. And we lost sight of her and I said, "I don't know where she's gone, I'm very worried about her" and then she came by on the trolley thing, on the cart, with three other elderly people, really cheering and waving as she went past. She was going, "that couple, they're going to get married!" So I'm having a laugh about this man because it's the first time, I think, since this break through a few years ago and certainly since Paul that I've noticed that ... I wouldn't mind seeing you again.

And are you going to see him again? Have you exchanged contact details?

Well we have exchanged contact details but actually he asked me what I do and that's how thalidomide came up, I said, "I've done this campaign but actually that's over now and I've started a new business and my new business is to do with the vocal cords and it's for singers and it's a new remedy to help with the vocal cords." And he said, "Oh, oh, I do karaoke." And I started to laugh and he said, "No, I do it properly." He does it properly. He said, "I should try your stuff." And I said, "All right then, do you want to buy a bottle? You can buy a bottle if you want." He said, "How much is it?" I said, "Oh, it's fifty six pounds." He said, "Oh, okay then." He said, "I'll just give you sixty and that will cover the postage cost." I said, "Fantastic." I sold my first bottle on the plane, just like that. Then of course I had to send it so he gave me his card but he was giving me his number anyway. So I've got his number. He can give me a call if he wants. I've sent the stuff off. I'm not going to go chasing after him. The only person I still want to chase after is this other man in Tunbridge Wells which is very sad. I don't know why I want to chase after him.

So I've got myself in a bit of a mess in that way. People sort of seem to think, "Oh Mikey you can just go and pick up any man." It doesn't happen like that.

It's not like that, is it?

No.

I think especially as you get older and as you've had children and as you get more defined in terms of your personality it's not really that easy to find people that are ... without even being perfectionist about it, it's not that easy to find people who are just right.

No, that's right. And just for that magic to happen. It just seems harder for it to happen because you just can't be bothered really, you know.

Because you could be quite happy without as well. Rather than ... you'd rather be on your own than be with the wrong person.

There's no compromise. The only compromise I might have with somebody is if I really got to like this bloke a lot, my compromise would be that he can stay in London and I'll live down here and we can ... there would be no compromise if he came to live here. If he came to live here he would have nothing to do with the children. I wouldn't compromise that, I just wouldn't. Not interested. If somebody was to live with me and the girls then we live together and I won't compromise what I feel is right for me to do.

I remember ages ago ... I can't remember if Paul had gone. I met a man on the aeroplane. Paul must have just gone. And it again was an Israel flight and we were talking about the toilets because actually that's a really good meeting place, toilets on the aeroplane and he said that he had ... his wife, his girlfriend had just given birth to their baby. It was his third child but their first and she wasn't Jewish and there was an illness, a death in the family, and he'd had to fly out to Israel very quickly and she had said to him, "What do you mean you're flying out to Israel? I've just had a baby." I think the baby was about five or six weeks old and he said, "Yes, but I have to fly out to Israel" because people get buried, don't they? And they were fighting because she said, "No, you must say with me." He said, "No, I have to go." It was a very close relative, it wasn't his mother or his father but I think it was the uncle or the aunt who ... it's like this woman that I went to see in Israel this time ... I might fly out to her funeral because she was very, very close to me and there's some people you just go to, you don't question it. I don't know if that's just a Jewish thing, you just go. I mean even El Al leave spaces for that to happen. You can get on a flight to Israel because you've got to be there. The minute you hear that they've died, you've got to get on that plane because they're going to be buried the next day, aren't they? And he said ... I don't know what the connection is, he said, "I don't know how this is going to work." He said, "I've had to fight just for being Jewish, just for going out," and I just thought, "I never, ever want to have to have this fight."

This man on the plane, again, it was like he's lived in England so long his reading English is better than his reading Hebrew now and he's flying out every month now to his father because his father's ill so he flies out and he spends five days or four days in Israel but it's not what other people do.

No, maybe not.

It doesn't seem to be, Ruth. And you understand it, you're Jewish. It's just what you do, isn't it? That's why I'm surprised that Nick's not going to Guy's thing, I'm really surprised on that. It doesn't surprise me that Geoff doesn't go because he doesn't have that same mentality.

No, I know what you mean. It's a different ... probably a different family connection thing, isn't it? Hard to put it into words. Okay, right, now ...

So men, that's my story of men.

Men, that's the story. Okay, what about any health concerns or medical problems as you're getting older. Have your pain levels changed? Have you found anything's changed on that score?

My pain levels are terrible. I have lots of pain most of the time but it's not the spasmodic pain like when you crick your neck. It's not the crick your neck pain, it's the, you know, I'm sitting here and I've got pain in my knee going down my leg and at some point I'm going to have to uncross my legs and kick them around and I get pain in my back and I lose sense of where my left leg is now so I can be walking and it will just go numb and I don't know where my leg is and I have fallen over in the past from it. I fell in the house one day. I have pain in my shoulders all the time and I get pins and needles and I can't feel my fingers and, you know, it's … I've discovered people don't have that kind of thing. Now, I've adapted my house and made my house lovely so that I can manage it but I can still manage … I'm not like a wheelchair person who can't go … so when I went to my mother's apartment, for example, she's got a very small bathroom and a small toilet and it's a really complicated little toilet and dark and I can't really manage in there but I can manage, you know, whereas if I was in a wheelchair I couldn't. So I'm still grateful that I can squish myself into these places and do things but I couldn't do them permanently because doing them all my life has created a lot of the problems I have now.

So on one hand, when I spend time in England I begin to feel I can't cope any more, I need to be slowing down and not working so hard and I go to Israel and it's like, no, I can still work, I'm still able to work hard. It sounds like the door's open. It's not. So sometimes I feel I can't do anything any more and other times I can. I don't know if it's the weather.

It could be related to the weather in terms of joints and that kind of pain, with the dampness in the air.

But there's also that feeling of when you acknowledge some of your problems, they can weigh you down whereas if you don't acknowledge them it doesn't occur to you to not do something and then you become ... the more you do, the less pain you have because you keep your body oiled. But there's a point where you tip over because you do too much and then it causes the pain. In Israel it was quite easy because my mother did all the cooking and I just sat around and I didn't have to do anything but I can't live that life, that was on holiday. So I have my PAs who come here and help me do those things but I've still not reached the stage where I have the PA come and cook in the evening. Perhaps if I did I'd have less pain and I could work more. So my pain levels are pretty bad, yes.

Do you have to take anything for it?

I resist everything and I do exercise and I do pilates and it costs a packet to keep doing that but it helps keep everything at bay.

Yes and keeps you very trim as well. You are very trim.

Well I am trim but it's all settling on my belly, you know.

I can't see anything.

[Laughs].

Not a single bit. Okay, we're onto the last few questions now. Any thoughts about the recent Grünenthal 'apology' I say in inverted commas, that you would like to share?

Absolutely. Without a doubt I would like to share what I think of that. Well Grünenthal didn't apologise. Grünenthal apologised only for their silence and they said it was because our fate so shocked them. And I think with anything when you make a mistake, it can be very hard to apologise, you don't want to own up to your mistake. You can say, "Well, if I apologise then it means I'm liable and if I'm liable I'm going to lose my business and I don't want to make that confession." But for fifty years they ignored us, but they not only ignored us, they treated their thalidomiders really badly and they perpetuate a lie and the lie is that they did the testing that was relevant at the time. They didn't. They did nothing. They made up stories, they bullied Distillers, made Distillers do things that they just shouldn't have done but everybody's passing the buck onto somebody else and then Grünenthal took no responsibility for what they did.

They've tried to lie, they've hidden everything, they've got the government, the German government, on their side, it was more important, their wealth, than the wellbeing of all these people they damaged and the tragedy of Germany and all these other countries is that when you look at somebody who's born with a disability, you see them as a disabled person and you value their life as that disabled person which is what Grünenthal did. They never understood that they were perfect human beings with everything going for them and that a disabled person's life is every bit as valuable as an able-bodied person's life and an able-bodied person can earn way more than a disabled person and they never valued any thalidomiders as an injured person. They just see them as a, quote, 'disabled,' unquote, person and that makes me so mad that they persist in that.

And that statue, I just thought that statue was grotesque. It didn't represent anything. It represented agony, it shows this woman, this thing, with this pain on its face and him standing there going, "Well, we've done nothing wrong."

Why didn't they consult people about that statue? Because I've not met a single person yet who has anything good to say about that statue. You'd have thought there would have been a bit of thought about asking the people who could actually say what kind of a monument they'd like to have.

Well, it was done by thalidomiders. The statue was not done by thalidomiders but thalidomiders in Germany got Grünenthal to talk, to come to the unveiling. You've got such a split going on in Germany, similar to England. You've got people in England who go, "We shouldn't ask Diageo," who was Distillers, right? "We shouldn't ask for any more money, they've been very good to us. We shouldn't ask Diagio for any more money because they might stop giving us the money that they're giving us. We're so grateful to Diageo." So what you've got is ... then you've got somebody who says, "Diageo never gave me the money I should have had so I'm going to ask them for more." This is all in that legal action that's going on. And what you have in Germany is that everybody fights each other, everybody's angry, everybody has got a different story, you know, it's the same with all of us. And some people are going, "We're not talking to you Grünenthal, you don't care about us. We will only talk to you when you agree to give us financial

compensation. Do not talk to us about charity, do not talk about projects, do not talk to us about being so generous to us because we give you three hundred and fifty Euros a month or a thousand Euros a month. Grünenthal you don't even do that, that's the government. Oh, you paid a hundred million Deutschmark did you, in 1972? What a generous company you are." There's those people who go, "We don't appreciate ... we're not grateful to you."

And what happens is that Germany has fought ... all the Germans fight, they squabble and it's a disaster area. And it's the same in England, it's only really a few of us who go, "We're not going to get involved in that and we're going to get involved in the campaigning." What's actually happened in Germany is that a group of people decided to talk to Grünenthal and they were the ones who brought that forward. And Grünenthal says, "Now, thankfully, the thalidomiders are talking to us." It's like, "No they're not, no they're not. You're still not offering us anything, you offer us projects and we have to tell you how much money we have and you have to decide whether to give us that money or not and you, Grünenthal get to decide whether our need is valid or not. Who the hell do you think you are?" You know? "You put your hands behind your back for the day and get dressed."

You know, I watched a woman, right, a woman who does ... I'll tell you who she is, her name's Mama Gina. She changed my life, she changed my life. I had no idea about being a woman and about sensuality and it's like, "Oh, she means me." Because I thought, "She doesn't mean me." And then I turned the page and she goes, "Yes, I'm talking to you."

[Laughs] Am I going mad?

[Laughs] She absolutely got me, you know, but she didn't get disability. And she and I … I went backwards and forwards to America. But I watched her on a video about a year ago and she put herself in a wheelchair and I haven't spoken to her … I wrote to her but she didn't write back to me and I'm really sorry she didn't. But she was in a wheelchair in her apartment and then she needed to get dressed but she couldn't get into her wardrobe. Anyway she gets dressed, obviously she gets out of the bloomin' wheelchair and gets herself dressed. But it's like, "No, no, no. Wait a minute. Your day should now be what are you going to do?" Right but she wanted to show how it was. So she goes down to her local café and then she realises she can't get into the café, they have to come out and serve her. But she didn't like that, "I always go to the café. Oh my God." And then she tries to hail a taxi and twenty go by, available taxis, before one stops for her. They don't want a wheelchair person in their taxi.

Too much hard work.

Exactly. And the whole moral thing, the whole of how invalid you are, invalid you are seen as ... so Grünenthal still haven't got it and I just think their apology was a bigger insult to the thalidomide community and I was so disappointed. I thought finally they might do something. In fact, when I first read that apology, I didn't have my glasses on, then I thought I had read it wrong and I had left my glasses behind. Then I couldn't read it until the next day when they wanted to interview me, the BBC and everything. I thought, "I've got to read this apology" and we expanded it on the screen and my girlfriend and I were standing back, neither of us had reading glasses, we couldn't read this, shining a light on it, somebody help! [Laughs]. "Oh, I did read it right, I did understand it."

No, I was more hurt by their apology than I ever felt by the company because they were just pushing a story fifty years on about how good they were and as though they had never done the right thing. And Grünenthal has never done the right thing.

Yes. Thank you for that. Okay ...

Do you want to call a taxi?

Maybe I should, yes. Hang on, I'll just pause for a second.

[Break in audio].

How have your feelings about your impairment and thalidomide and its effect on your life changed over the years? And how do you think you see that aspect of your life now as you're older than you did when you were younger? Have you become resolved in any way? Angry?

Ruth, I'm not quite sure.

I think it's probably one of my least favourite questions to ask.

It's a massive question as well because it's ... how do I feel? I still get shocked when I see pictures of myself. I had a moment the other day when I was dozing in the sun in Israel and I turned round and I saw my hand and I thought, "That's never going to change now." I think I probably believed one day when I grew up my arms would become normal.

That's a very interesting thought, I've never heard anyone say that before.

Oh, right. And it's like, "I think I am grown up now, they're not going to change, this is it." And ... okay and it's kind of like, okay. And I know for a fact if I didn't have my disability I could have had loads of men now, going out, you know, you go out on the social scene, we look at each other, we like each other and it can start whereas people don't look at me because they're afraid and it only takes being engaging with me and talking that people become interested and then, you know, my brain is quite empty at the moment because I'm menopausal or I'm full of the thalidomide campaign and I've got nothing interesting to say to anybody, that's my feelings. So I'm not there, it's not so easy on the market.

And one of the things I would have liked to have been was in the forces.

Really? I never knew that.

Yes, it's just something ... I don't know, I like uniforms. I'm not really quite sure. But I have no idea what forces I would have liked to have been in or what role I would have liked to have played but I know that I couldn't play those roles and I'm also very aware that my life is affected by my disability through choices that came out. I couldn't get a job as a computer programmer which could have taken me places but my life

went somewhere else. But I love my life and I think I've had a great life but I think now because of my disability I've achieved things that I couldn't have achieved.

I remember being with Rowland Bareham, who's a thalidomider, and he worked in the Home Office or the Cabinet Office, I can't remember which Office it was. And he walked me round the building. We went to this room and we looked out the back to 10 Downing Street and we looked at each other and suddenly we both got the giggles and it's like we're only doing this because we're thalidomiders. None of my mates could do any of this, you know. So it's taken me places – going to Parliament, talking to ministers, none of my friends have done that, you know. So I love all of that.

So it's closed some doors and opened other doors.

Absolutely.

But maybe not the ones you would have chosen.

Absolutely. And I actually said to a friend some years ago, I actually ... he told me a story about the man Simon, I think his name was Simon, who got blown up in Argentina. He was on the boat that got blown up and he got all these burns all over his face.

Oh yes, he was a young guy at the time, but he's been around a long time.

Yes and he became a speaker, an empowering speaker, and as my friend was talking about him, one of the things that this bloke realised was that all he wanted to be was just a Private in the Army, he didn't want to be anything, he didn't want to go anywhere, he just wanted to go and fight. Just go and fight. And, of course, he survived this terrible bomb blast and it forced him into a place ... I can't remember how the rankings go in the army but his commander, he was in the hospital, and his commander came in and said, "Are you coming to the rugby?" And he went, "No, no, no, no, no" because he thought everyone would stare at him and be horrible. But actually what happened was this commander said, "No, you are coming" and took him and everybody knew he was coming and everybody knew him as ... I think his name's Simon, you know, "Hi Simon!" Not, "Oh, hello Simon ..." there was none of that, they all just treated them well and he grew from that moment and he's now an empowerment speaker.

And in that moment, my friend was talking about it, I thought I never asked to be disabled and I never asked to be a leader and I never asked to be any of those things. But actually I am a leader and I am disabled and I have to take that position, my place in society, that's my place. I may not want that, but actually that's what I've got and that's when I became Chair of the NAC. I just drove myself to become Chair of the NAC and to be really, really involved in the campaigns. I was already involved in the campaigns at that stage.

And I still sometimes see my disabled life and my able bodied life and I'm not quite sure what my able bodied life is, my able bodied life is probably this fantasy. A part of me thinks that this man I really like in Tunbridge Wells would like me if I was able bodied, I don't think he can handle the disability because it highlights his disability and I understand that feeling. I had that feeling when I was younger. I think lots of us did. So I don't really know how to answer your question. You've answered it fantastically.

Oh, have I?

You have, yes. Absolutely fantastic. And, in fact, it is time to stop and I think that's a really good point to stop on, with what you just said there apart from to ask you is there anything that I haven't talked to you about that you wish that I had asked more, or you feel wasn't covered?

I remember thinking that last time but I can't remember what I thought and now I've read that transcript ... I was blown by the transcript, I have to say. So perhaps I need to wait for the transcript.

We can always do another follow-up. But if something comes up ...

That I think is really important to go into the archives for the rest of our lives. There is something but I can't think of it right now.

Okay. All right well let's hold that thought and see if you remember when you see the transcript and we can always meet up again. But thank you ever so much for today, fantastic insights as always. Thank you.

END OF RECORDING