

Thalidomide: Ed Freeman (2012)

Ruth Blue interviews Ed Freeman for the *Thalidomide: An Oral History* project.

The library at Wellcome Collection

183 Euston Road, London NW1  Euston, Euston Square **T** +44 (0)20 7611 8722

**wellcome
library**

wellcomelibrary.org

The free library for the incurably curious

Wellcome Collection is part of the Wellcome Trust. The Wellcome Trust is a charity registered in England and Wales, no. 210183. Its sole trustee is The Wellcome Trust Limited, a company registered in England and Wales, no. 2711000 (whose registered office is at 215 Euston Road, London NW1 2BE, UK)

Okay, this is Ruth Blue interviewing Eddie Freeman ... do you like to be called Eddie or Ed?

Ed.

Ed. Interviewing Ed Freeman on the 24 July 2012 at his home in Swindon for the Thalidomide: An Oral History Project.

Ed could you confirm that you've signed the copyright and consent forms?

I have, yes.

And could you first confirm your full name, the date and place of your birth.

Edward Dennis Freeman, the 8th of August 1959 and I was born at number seven Melne Road, Stevenage, Herts.

And first of all if we could just talk about your family a little bit. Who your parents are, what sort of work your parents did and brothers and sisters.

At the time of my birth, my dad was a bus driver, my mum was a housewife. I had an older brother who's nine years older than me and an older sister, seven years older than me. My brother's name was Pat and my sister's name is Sue.

So you were the youngest?

Yes.

And thinking back about your parents' decision to use thalidomide, do you know who prescribed the drug for your mum?

Yes, it was the GP. His name was Doctor Dugdale who, I've been told by my mother ... his wife was also pregnant at the same time as when he prescribed the drug.

And did he prescribe it for his wife as well do you think?

I don't think so. I'm not sure.

And do you know what it was prescribed for?

Yes, my mum had sort of a pneumonia type thing because she's quite adamant ... the social stereotype is that it was for morning sickness but it covered a load of different reasons why it was taken.

And do you know how long she took it for?

She took two tablets.

Was that sort of at the start of the pregnancy?

Yes.

And did she ... do you know if, at that period of time, your parents had any concerns about using a drug during pregnancy?

Not at all. It was back in the time when doctors were tin gods and were infallible. So if a doctor said, "Take this" you took it.

Yes and did she know anybody else who was also taking it?

No.

And outside of her having pneumonia do you know that she had ... if she had a good pregnancy in general?

She had a very good pregnancy. Apparently my brother and sister weren't planned so that was that. But with me I was actually planned and my mum said that she done all the right things, ate all the right foods. I think she gave up smoking at the time, didn't drink, done all the right things. So she had a good pregnancy.

And did you ... as time went on in later years, were you ever able to sort of discuss with your parents about their decision to use thalidomide?

It wasn't ... yes, we did discuss it, obviously, to a degree, still touch on it. But it wasn't, "Why did you use it?" as in, "You know this was going to happen." That wasn't ever ... you know, that never came up. She took it because she was ill and she believed, as everybody did back then, that doctors were infallible so that was that.

Yes. Going on to talk about your birth. You already said where you were born. So were you actually born at home?

Yes, I was, yes.

And do you know how the birth was for your mum?

Apparently quite an easy birth. When I was delivered, the midwife was shocked. I believe her name was Hutten, my mum told me. She told my dad that I was born without arms and legs, obviously Dad was shocked. He told my mum and my mum didn't believe it because she said, "But I could feel him kicking inside." And that was it really.

I was then taken away to Lister Hospital in Hitchin which is the next small town along from Stevenage and that was it really.

And has your mum ever talked about ... so you said she didn't believe your dad at first, and has she spoken about how she felt when she realised you had been born without arms and legs?

Well, initially, I think like most mothers, she was knocked out basically ...

Sedated you mean?

Yes. For a couple of days. To get over the shock I suppose. But my mum and dad ... they come from very close families and it's a case of what will be will be and, "Yes, he's got no arms and legs but he's still ours." So that was it, yes.

And so why were you sent away to Lister Hospital?

I suppose it was panic, really, going on. My dad was obviously panicking, my mum was sedated, the midwife, I think, was running around like a headless chicken. The GP was totally unused to anything like this so they took me to Lister Hospital, which was the main hospital at that time, where I was seen by a doctor called Liness who then told my parents that basically to leave me there where I would either pass away peacefully, which I have now learned what that means, they just starve the child to death, or they would put me in a home because I had no future. I was a vegetable, they said.

And what were your parents reactions to that, then?

Well, when my mum was up on her feet, after a couple of days, they came and visited ... because I asked this the other day, I wanted to know what went on and they came and visited me every day for, I think it was two weeks, with my brother and sister. Because my dad took two weeks off work to be with my mum so he was able to drive backwards and forwards. So they came to see me every day and then, because it was a hot August, the nurses in the hospital left me in the garden where I got sunburnt and my mum just saw that

I was sunburnt and said, "Okay, this is it. You know, medical profession or not, this is still my son" and just took me home and that was it.

And can you describe, for the interview, what your level of impairment is?

I'm a four-limb phocomelic, as they say. But back then when I was born I was rudimentary limbed. It changes as time goes by. Basically I've got flipper like hands attached to my torso and flipper like feet attached to my torso also.

What do you mean it changes over time? You mean just the terminology?

Medical. Medical terminology.

Yes, yes, yes. And do you know what advice your parents were given by medical professionals after your birth?

Literally just either, "Let him die or put him in a home and have another child" basically.

And after you were brought home, did they receive any kind of follow-up care or support?

Again, I asked my parents ... or my mother because my dad's died. I asked my mum this and, to my amazement, nothing. It was just like I was an ordinary baby. There was no sort of counselling, nothing.

And did your parents talk about how they felt about that being suddenly, you know, with a disabled baby which they'd not had to experience before, did they talk to you about how they dealt with that?

Not really. They've always seemed quite straightforward and took it well, you know, "This is what we've been dealt, this is what we carry on doing, you know." And they brought me up totally as normal as my brother and sister.

That's very good to hear actually. So you had two weeks in hospital and then you came home and was your mum ... did your mum stay at home with you to look after you?

Yes, she was a housewife at the time.

Yes, yes, yes.

They did that back then [laughs].

Yes, no, I know. If only! And do you know how siblings and other members of your family reacted to your birth?

My [dog barks] sorry, that's my dog. My siblings, incredibly well. I had some negativity from both sides of my parents' families. One suggested, on I think my mother's side, that I should be put into a home. And on my dad's side, an aunt came out with a lovely quote like, "Well, don't worry too much because as he gets older, he'll be able to join a circus." But this was back in the ... you know, the late fifties / early sixties when people had different concepts, totally different concepts of life.

It was very different, wasn't it? And do you know what sort of impact your impairment had on your family's general life in terms of looking after you?

I think it had quite a big impact. But talking, as I said, to my sister and my mum the other day, because I knew this was coming up, my sister said it didn't have a huge impact. But I can't imagine how it didn't because after the age of two and a half, I then started receiving medical interventions with artificial legs / arms etc. and therefore my mum would have to come into hospital with me for long periods of time leaving my sister and my brother with my dad. And to take the mother away from my siblings it must have affected them but my sister said it didn't and that...she actually said that all the affects were positive.

I suppose if you were the youngest child they might have had quite a protective attitude towards you anyway.

There certainly was that. My sister treated me as a doll because obviously I was smaller than average and she, because she's seven years older than me, yes she would treat me as a doll and she'd feed me and change me and stuff like that. When I got a bit older my brother would just torment me like any other older brother would so, yes they were good.

So, I was just going to go on to asking you about medical interventions. So that started at the age of two and a half...

Yes, I think I went to Great Ormond Street to be assessed. It was also around the time that the GP, Dr Dugdale, came to my home and said to my Mum "Did you take thalidomide?" and she said, "Hold on," disappeared up to the bathroom medical cabinet and she still had the tablets. Because, again, in those days they never threw away tablets, you know, so she had absolutely one hundred percent proof and so from that point on I was taken to be assessed at Great Ormond Street ... I stayed there I think a day or two and then after that, shortly after that, I was sent to Roehampton.

So the first moment your parents realised that your impairment had been caused by thalidomide was that moment about two and a half years later when the doctor showed up?

Yes. Roughly about two and a half years later and that's when apparently my dad got angry because up until then he thought it was just nature but when he found out that it was a man-made incident that's when he got angry.

And were they aware of stories coming out in the paper at that time, of other children being ... ?

Well, being one of the oldest I was one of the leading stories so they didn't really have a lot to read because it was my age group that was in the papers first.

It was just newly hitting the headlines ... it's quite extraordinary to think that for that two and half years, or two years, your parents, I mean they obviously did a fantastic job, but didn't receive any help or support.

I was amazed by that ... amazed. I mean they got all normal GP, you know, weighing the baby, that type of thing but nothing to do with my disability at all.

Yes. So you would describe yourself generally as having had a happy childhood.

Very happy.

Okay, so you've already answered some of my other questions which were how did your parents feel when they realised that taking thalidomide had caused your impairment, so, your father got angry.

Yes.

And did they become involved in any of the campaigns for compensation ?

Yes, they joined the group. They weren't forerunners, they were more supporters but yes they certainly lent their weight to the campaign.

So in terms of medical interventions, you went to Great Ormond Street and you were assessed and do you know what that assessment consisted of, what was it?

Not really... I think it was just a medical alarm bell went off, you know. I think probably by this time they'd had a few more in and I get the impression the alarm bells were ringing and they wanted to know what was going on so they brought me in to assess if I was thalidomide.

And then after that you said you'd spent some time at Roehampton.

Yes I spent quite a bit of time at Roehampton in the early days, yes.

Was that fairly soon after Great Ormond Street? What age were you?

Fairly soon. I should think I was about three-ish. Yes about three-ish ... initially we ... initially they didn't know what they were doing and so they opened up a ward at the bottom of a military officer's ward there was just a spare room going and there was about five or six of us and I think it was a case of not putting us in arms and legs straight away but just seeing who we were, what we were. So that went on for a little while and then after that they decided to give us artificial legs and soon after that it was the arms.

And what was that like, being sort of fitted up for those arms and legs/ Do you have any recollection of that?

Oh [laughs] yeah. It was ... it's a two way thing really. I liked the legs. I hated being fitted for them though because how it would happen is we would wear a sort of a 1920s bathing suit and be hung up on a, like a meat rack, while the limb fitter would cover us in plaster of Paris. That would then dry ... after about an hour or so, that would dry then they'd mark it with a blue pen where that had to cut it away. The only way I can describe it is like wire cutters, big, big wire cutters to cut the excess plaster of Paris away and although they'd never cut us, they were very good, but it would leave a lot of bruising ... a lot of bruising.

It must have felt quite frightening as well, somebody coming at you with big...

It ... yeah, well, you got used to that and it was all the smells as well. Even now if I smell leather, or plaster of Paris, it takes me right back to the hospital.

And how many times do you think you had that procedure done, being put in a cast?

Probably about eight times. Sometimes they'd make a cast and it wouldn't be right so they'd have to do it again. There was a lot of sitting around waiting for them to say, "The cast is okay." Just a lot of boredom, really.

And did you have to stay in at Roehampton at that time?

Yes.

And was your Mum allowed to stay with you or did you stay on your own?

No, back then they didn't have any facilities so my Mum stayed with a cousin of hers who lived in Islington and every day she would get the tube through and then the bus so I'd see her every day until the night time and then we ... then they built the Leon Gillis ward and that had bedrooms for the parents to stay.

Right. And how old would you have been then, roughly about this time scale?

By then I was about six.

Right.

Six or seven.

And what was it like having to be separated from your Mum in the hospital?

It was awful because when you're only a little kid it's ... because at the same time there were kids there that were in homes and they ... you know, their parents would visit them and then disappear and wouldn't be seen again for another six months and so in the back of your head although I knew my parents weren't like that but in the back of my head I thought, you know, "Am I being dumped?" so there's always that ...

... anxiety there.

Yes.

And did you get to know some of the other children whilst you were there, did you from like a ...

Oh yeah, close bonds, yeah.

... and so meeting other children in the same situation was important.

Yes. We were all on a level playing field sort of thing. Yes, I mean it's formed a bond, no doubt others have said it, is we are more like a family than friends and we may not always get on with one another but we're always there for each other.

That's what happens in a family, isn't it? You don't always get on.

That's right.

And so the trips to Roehampton for limb fitting started around when you were three and continued in the Leon Gillis Unit after you were six and do you know how many more times roughly you would have been going back and forth there over those years?

My last pair of artificial legs was at the age of ten. Those are the ones that you saw at the Wellcome Trust and I was then ... because I went to a state school, I was told that my teachers would refuse to accept me if I carried on wearing legs because I was constantly falling over and they couldn't put up with the stress. So they said, "He either goes into an electric wheelchair or we can't teach him any more." So at the age of ten I gave up the legs, which was sad at the time because I'd grown up with them, using them, but in hindsight the best thing could ever be done.

What was it like using the legs? You say you liked them but was it that feeling of normality or height in a crowd?

Height I suppose but it was quite a nightmare because I had no arms to put out to stop myself falling, as my Mum said I would just go down like a tree and anything in the way I would hit. So cuts and bruises were quite common and then what people don't realise is that the legs came in two halves and when you fell, these two halves would squeeze together and ... let's say it wasn't too pleasant round the genitalia region and then you'd get the teacher picking you up and rubbing your head and you'd think, "That's not where it's hurting, that's really not where it's hurting" [laughs].

Oh no ... what about the arms though? Did you ever bother with the arms or... ?

I did. I was encouraged to use the arms. My parents didn't like me wearing the arms, they know they were no good but the medical profession knew best and I tried them for probably about a year and they were absolutely useless, absolutely ... can't see the point of them at all.

No, and what about ... [Phone rings]

Oh I'll get that ...

Just wait a minute for that to stop...

I should alter that but she sounds much posher than we do.

It sounds quite good.

That's my ex-wife.

Okay, she sounds friendly too.

She is. Moving on.

And were they very heavy, the arms?

Extremely heavy... they were ... I can't knock them, they done the best they could with the materials they had at the time but they were made out of metal ... a metal waistcoat with metal tubular arms, hooks at the end, as hands, and they were powered by gas so you had to wear two gas cylinders on the back of you. And when you're only five / six it weighs a tonne and then with the legs on as well, it was just impossible.

Well, I can imagine, trying to get around with the arms and the legs at the same time.

As an example, when I was in Roehampton we all ... most of us there had short arms or no arms, some had legs, some like me didn't but we'd all be wearing these artificial arms and then we'd all sit at this long table feeding ourselves with these long arms and these special spoons they invented that swivelled because you had no swivel on the thing. And we were starving because we couldn't feed ourselves and then what would happen is at point the nurse or the physio would leave the room, we'd quickly throw off our arms, eat with the arms that we had, put the false arms back on again and they'd come in and go "Oh, how well you're doing with them" and you'd just think, "You just don't know..." [laughs].

That's one of the craziest things I think, that I hear about is this attempt to normalise children when you were already normal, you know, for yourself, so...

The thing that annoys me most is that physios never put us all into a room and watched us play without the metalwork on. If they'd watched us play and saw what we could do and if they could enhance that, great, but if couldn't, don't add metal to it. We could all feed ourselves with what we had, even the ones with no arms managed to feed themselves. It's natural, you either do it or you starve and you find a way and with the artificial limbs, they just held us back, it was like being in a straitjacket.

It's interesting isn't it? And were there any other gadgets that they did provide you with that were useful like dressing sticks, those kinds of things?

That was quite good. They did supply later on dressing sticks, telescopic ones which could be just discretely put in a pocket or something, small things like that but they were chosen by us. You know, we said that's what we want ... it's not forced upon us.

I suppose that's how it should have really worked, shouldn't it? Sort of enhancing what you've got rather than trying to hide it.

Yes, but a lot of these physios have just come out of university, life skills weren't really there but they were going by paperwork which is a shame, but there you go ...

And did you have to have any kind of surgical interventions at all?

No, I'm one of the lucky ones. It was offered ... they offered to cut my feet off so they would fit the artificial legs better. My parents refused that, their quote was, "He hasn't been born with a lot, don't remove any more," which I'm grateful for. And then, I personally think, and so do my parents, that they wanted to do an experiment by removing a stiff finger I have on my left hand which is not a great deal of use but they wanted to cut that off and re-attach it onto my right hand so it would look like I had a normal hand on my right-hand side. My Dad asked if it would be functional and they said, "Of course not." It would just be dangling there.

So what would the purpose be then?

I think experimenting ... just to see if it could be done, grafting.

Because you wouldn't gain anything from it.

No, absolutely nothing. So that was refused as well thank God.

At what point do you think that you knew that your impairment was due to thalidomide?

I can't ever remember not. As I say when you're only that young you're mixing with other thalidomide kids, we were very much in the media all the time at that point so yeah, grew up with it.

Were you parents approached by the media to discuss your story?

Yes, again because I'm one of the oldest ones and because I'm four limbed I made good photographic statements.

And did that have any effect on any other people you knew or people around you that you were, you know, in the newspapers or the news or something?

No, I think all of us got a lot of support until of course the compensation came along and then the support sort of went to a little bit of jealousy and that was it really.

What about the Thalidomide Society events, like the sort of AGMs. Was that something your parents were involved with?

Oh yes, right from day one, yes.

So you went each year to the... ?

When we were older, yes. Initially it was set up more for the parents. I always tagged along because my parents took all of us everywhere. I can't remember a great deal of it because I was too young but it was more meetings than anything else, no social side of it.

And did you think your parents... it was helpful for them to meet other parents with ... ?

Oh absolutely, yes absolutely. My Mum is still friends with many of the parents that are fortunately still alive. So yes it was a good support group, a much needed support group.

And what about you, did you find peer support helpful still?

Yes, I mean the first time I went to an AGM ... because initially they were separate ones all over the country, so the first national one was in Llandudno, North Wales, and that's when I came up against a whole host of thalidomide kids. Up until then it had been about five or six and then all of a sudden you're meeting about twenty five / thirty and that was a bit of an eye-opener.

In what way, describe what was that. What was eye-opening?

Seeing people identical to yourself and that was it really and then you've got a common bond. [dog barks].

So you said about your education ... you went to just a regular mainstream primary school?

Yes, my Dad insisted on that. There was a school just literally round the corner from where I lived and they said, "Yes, yes we'll take him, no problem" and then just before September when everything started they said, "No, we can't take him." The teachers had refused so my Dad had a mad panic rush on and fortunately he found another school, Pin Green Infants stroke Juniors, which was about a mile away and had a brilliant Headmaster, Mr Plumber, always remember him, who had the insight to think outside of the box, I suppose, and said ... and accepted me.

Tell me a bit about what it was like at Primary School.

It was good ... they obviously knew, I mean I didn't go with simpletons, they knew I was disabled. My Mum would walk me the mile there without my legs on, I was in sort of a pushchair then when I got there she put my legs on, the kids would see me putting my legs on and after I think the initial, "Oooh, ahhh what's going on?" that was it, I totally fitted in and they'd, you know, muck around, like kids do. I had, in those days, I had what we call ski legs because the balance wasn't that good so you had a sort of a wooden foot and then a long ski underneath and for a joke, if I was walking along, my mate would stand on the back of it, stop me. They'd also put down those great big crayons that they used to use in those days just to see if I'd fall over but it wasn't done maliciously, it was just like you'd do it to any kid and it was good.

And did you have any help, when you were actually at school, with things like using the bathroom or anything?

No. None at all.

You were completely independent?

While my Mum was with us at Roehampton she invented trousers ... because again it was a whole new ball game, nobody knew what to do, so she used to be ... make handbags, so she was great at sewing. And she invented this pair of trousers with a flap front which was done up with Velcro which was a brand new material at the time, it had just been invented with the space race thing. .and then it had a long cord which I could bend down to reach the cord, open, go to the toilet, close again. So I was okay.

And she invented those ... ?

Yes.

And did other people take that on as well, to use?

Yes, a lot of people took them up.

And what about things like eating at school... all of things were just normal?

Not a problem, not a problem. The food would be obviously brought to me... I think they were brought to everybody actually when we were kids, little kids.

Yes, I've always been able to eat from as early as I can remember. My brother and sister used to help me a lot. They'd help me with doing things and also with the education because they were that much older, they'd help me with the education, they'd help me do things and it was between my brother, my sister and my Dad who helped teach me how to sit up on the floor on my own and stuff like that. So I've always been reasonably independent, I had no sort of teacher, a TA or whatever they call it. I just mucked in with everybody else.

And things like writing and the sort of activities you had to do?

No problem. Obviously, I mean they tried to get me involved with PE which was sad of them really but most of the time I'd just sit and watch, stand there and watch. At playtime I was allowed to stay in because if I went into the playground while I had my legs on I'd be knocked flying, which was good ... and then they'd always ask a kid if they wanted to stay in with me, so a couple of kids would stay in with me and that was it.

Did you have any ... at school were any of the kids... did you encounter what we'd call any disability prejudice but, you know, a children's version of that, sort of bullying or unkindness?

Not at infant school, no. In fact, it's quite amazing looking back, there was more racism than there was disability problems because back then Stevenage was very much a white area, a white working class area and I always remember this young kid came into the school ... it was a little girl, she was black and she got more hassle than I did which was really strange.

That's interesting though isn't it, as well? And so the school didn't really have to do... they didn't really make any changes to accommodate your impairments... you sound like you fitted in really, really well actually.

Yes, it was fine.

And did you have any particular favourite subjects or things that you were good at?

Always been Art and English.

Yes, I can relate to that. We'll go on to talk about your artwork later on when we go to adulthood but do you think there was a sort of start to your interest in producing art even as early as primary school?

Well, it was my Dad and my brother, both are quite arty people and they would be drawing and doodling and stuff, nothing major but they encouraged me. I mean, they could see that I wasn't going to be a footballer and they would encourage me and stuff like that and then my brother was into American comics which is full of great artwork and it just spun from there really.

And you said ... so I asked you if you'd experienced any kind of bullying and you said, "Not at infant school." So after primary school you went on to like a junior school?

Yes. Junior school was fine also... all the way through that was fine.

Was that the school where you had to stop using your legs?

Yes. The juniors and the infants were joined. You literally went through a door and it was, "Oh, I'm in big boy's school."

And then at the age of ten I went into an electric wheelchair. I was held back a year because I was going into hospital so much I wasn't receiving all the education I should have done but at the ... when I hit about eleven, I should have stayed on another year but my headmaster says, "Well, he's done the exams, he's passed it. I think he's ok for senior school." So I left my mates in my class and jumped up a year basically,

so I left them all behind at school so when I went to senior school, where a lot of my junior school kids went I didn't know anybody so that was a bit awkward.

Okay. And what changed at your school that meant... so you started school in the infants and you were wearing your prosthetic legs and at some point in the juniors the teacher said, "No."

I think what happened was, when I was younger, lighter, the legs were lighter, I wasn't falling over so much and then as the technology evolved, the legs were getting heavier and heavier and I was starting to fall over all the time. During lunch breaks I would find there was ... in the class there was this tall pillar and then next to that was a chest of drawers and so I would work myself into there so I could actually rest, so I could put my legs ... rest it up against the pillar and I could put my back up against the thing and they noticed this, they noticed that things weren't going right and so they just said, "Look we've got to call it a day, he's got to go into an electric wheelchair."

And how did you feel about that, were you relieved to get rid of the legs?

No, not at all. I didn't see a huge problem and for a while I missed them because, basically, you know, you grew up with them. But in hindsight it was the best thing I ever done because they weren't good at all ... looking back they weren't good at all.

Do you think that people who have used legs for a very long period of time actually ended up with other physical problems?

Oh, absolutely. Hip problems, back problems. Again, in hindsight, you know it's obvious what's going to happen but they do become part of you and giving them up is like giving up a real leg, so it doesn't come easy to them so I can understand them, you know, keeping the legs on for so long, but ...

And did you ... did people's attitudes towards you change when you moved from having the legs to being in a wheelchair all the time?

Yes, they thought it was more fun because I was kid, I misused the wheelchair, which was supplied by the Council, so I'd go to school in a taxi by then and I'd use the school wheelchair... and back then they were acid batteries and I would go out in the playground and play football. But of course quite often the ball would hit the battery underneath, tip the battery over, acid everywhere. Kids would swing off the wheelchair, which I agreed to. When winter came I could go out and spin round and have fun and the kids would hang off the wheelchair so yes, they loved it, everybody loved it. It was like a huge remote control car.

Well yes exactly, it does have that side to it doesn't it?

Yes.

But in terms of getting around inside the school as well, was it all on one level, your school?

I was really lucky. Stevenage was a new town, built because of the war basically. There wasn't enough housing in London and so Dad was a London bus driver at the time and he was offered to go out to Stevenage ... there was a few, Harlow, Stevenage, Luton and Essex, they chose Stevenage. Brand new town, access unbelievable, everything was ramped, everything was accessible ... all the schools that were being built, especially Pin Green because that had only been up about a year before I went there so it was totally accessible.

That's very good isn't it? And did your school friends ever ask you about ... was it something that ever, I mean I know boys don't talk much do they, but did they ever ask you about your disability?

It only came up when it started going into the papers and they were getting information ... it was obvious they were getting information from their parents and they'd ask a little bit then but it didn't really mean anything, you know, kids were kids.

And then ... secondary school?

First couple of years, again, a joy. I have to at this point thank again the headmaster, Mr Kensy, who, again, thought out of the box. The school had been ... although Stevenage was a new school, a new town rather, the school I went to, Barclays School, was very old and really quite inaccessible but he not only accepted me going there, he had a lift put in and ramps put in, otherwise I couldn't have made it and then after I went there a lot of other disabled children went as well because it was now accessible. So I owe him lot for that.

First two years, very much a joy, you're playing around, you're not taking life seriously and then thirteen / fourteen all the hormones kick in with everybody and, you know, it's a minor war zone, you know, you get your cliques, like any normal school. I should imagine any school, once the hormones kick in everything becomes more aggressive.

Yes, yes. Do you think you suffered more from any of that, being disabled at the school?

Probably differently, not more, differently. The thing some of the kids resented was ... I obviously didn't use the school bus so I went by taxi. My taxi driver was a typical taxi driver and fitted me in when he could. So I was nine times out of ten late and these kids had to go to registration, sit in the hall and sing hymns and then go to the class ... I would turn about ten minutes late, having missed everything, and after a while they resented that, you know, "Why are you always late? How comes you get away with it?" and stuff like that.

Right, so they didn't like you getting what they thought was preferential treatment in some way?

Yes, yes. I mean, the fact that I had a lift built for what seemed, for me ... they must have thought I was little Lord Fontleroy ... and so it carries on.

What about friends at school... so like primary school and secondary school, did you have a good circle of friends?

I've always been on more of a one-to-one thing. Only two / three friends at a time but that's more choice than anything else really. I've never been a team player.

And were they the sort of friends that you could talk to, if you were concerned about anything?

Yes, all the way through. All the way through.

You mentioned something earlier about how things changed when you got the compensation, you were talking about the media and people being generally very supportive, but then when compensation came through you said things changed. Do you know how old you were when you got your compensation money through?

I was sixteen.

Sixteen. And did you go for an assessment, like a medical assessment to see what level of compensation you got that you remember?

Yes, the photographs and all that type of thing, yes.

How old would you have been when that happened?

I think that was probably when I was about thirteen, fourteen.

Do you remember that?

Not too clearly to be honest, no.

And so tell me what changed when the compensation came through at sixteen.

I mean it wasn't drastic but there was ... it was a working class area and so when the compensation came through people seemed ... or some people, not everybody... some people forgot what it was for and thought of it more as a lottery win and so there was a bit of resentment going on. But it didn't last too long, it didn't last too long.

And do you know what sort of effect getting the compensation through had on your family, your home situation?

Not a great deal really because the money was tied up. It was ... my personal allocation, I think this goes with most of the beneficiaries, you could have had a chunk at eighteen, another one at twenty one and then a final payment at twenty five. So it didn't really have a great impact, it just ... no, it really didn't have a great impact at all.

And were your parents interested and involved in what was going on with that story with the compensation battle going on?

Oh yes, all the way through, yes.

Did they talk to you about that at all?

Not really at the time. My Dad had a philosophy that he didn't want money as such but he wanted whatever I needed i.e. wheelchairs, cars, adaptations then the government just automatically write a cheque so he wasn't really after the money, he was after what the money could get. So that's why he had a different philosophy to most of the other parents who were after more of the money.

And your parents would have taken control of the money though at that point or was it left until you were old enough to control it yourself?

It was put into a trust, my own, not the Thalidomide Trust but my own trust which my dad was one of the overseers and his brother another one.

And finishing off the sort of the secondary school time and these sort of teenage years did you carry on at secondary school to be mostly interested in art and English?

Yes. And a little bit of history by then as well because, again, my Dad was a big influence. He loved history even though he couldn't always conceive it properly and he was what we would call now an amateur philosopher really and he'd do things like ... at weekends if he wasn't working ... obviously I didn't go out to play football or anything so he would read the Encyclopaedia to me and ... which was fun ... and historical novels and things like that. So my interest grew then and funnily enough it's been passed on to my youngest son.

So what's your youngest son ... is he studying?

He's doing obviously history and all the basic stuff but he wants to go into the theatre so he's very arty and my other son's arty as well because he wants to be a photographer, so it's all passed on.

It's interesting how these things pass on through the family isn't it? So at that point did you have thoughts about what you wanted to do when you were going to leave school?

Yes. I was very naïve like all kids are and I wanted to design record sleeves. We had records back then.

That's not that naïve to be honest... that's not terribly naïve an aspiration.

It was in the area I came from. I remember going to the careers meetings that they had and my school was offered two choices, you either worked for BAC or you joined the Army. That was the type of school it was so anything like, "You want to do record sleeves? No chance," you know.

Yes, yes, yes. I suppose it would be fairly hard to break into. And how about ongoing health problems or medical interventions going up to that time?

I've been seriously lucky, seriously lucky. I've not ... I went through a short spate when I was about fourteen of my back fusing and that caused a hell of a lot of pain. It didn't go on too long. I went to Harley Street and they said the best they could do was fix a rod up my spine with a fifty percent risk of paralysing me so... and then they said, "You've got that as a choice or you carry on with the pain and hope it goes" and then in a reasonably short space of time it fused as you're growing up, you know, getting older and I've had no pain since.

That's good. Gosh, that's a risky thing, fifty percent chance of being paralysed. And anything else up to this point of time, up to say the end of your teenage years just before going into adulthood that you think we should have covered and we haven't covered?

Only that I had a very normal childhood. At weekends I was in the streets playing with the kids because we lived in terraced houses with little front gardens and all the kids just went from one garden to another. I joined in with all that, we had a park at the end of the street and the kids would take me up there in either a chair or later on I got sort of a little electric car thing.

I've seen a photograph of you in the little car actually.

Yes. Which Lady Hoare actually bought for me from Triang if I remember rightly...

Do you know where that went?

Yes, we passed on to a younger beneficiary whose name I can't remember. Because a lot of things back then was passed down. Once you got too big for it, it was given to the younger kid so it was quite a good community like that. And at Roehampton it was ... I was talking to my sister about it, I said "It must have affected you" and she said, "No, it was such a great laugh." And we discussed things like most weekends, if

not every weekend my Dad would bring my brother and sister up to visit. And back then, before the Leon Gillis ward, we called it A Ward, they thought the high chairs we were in were too dangerous so they cut them down into low chairs with a little tray on the front and they put caster wheels on them and because my brother and sister were young, especially my brother, he was that way inclined, decided that this would be great dodgems. So they'd be about five or six beneficiaries all being rammed around this room and we loved it, it was brilliant, you know, smashing into one another it was just ...

Do you know I think Dr Fletcher told me a story about that, once he was sitting somewhere and there was a long corridor or something and he suddenly saw all these like thalidomide children just shooting past the doors ...

Yes, yes it was what we used to do. It was great fun.

So do you think it was quite a friendly place in general at Roehampton?

In the early days. Again, if I can give you some stories ...

As many as you like.

[Laughs]. In the early days the soldiers were still there, they hadn't been kicked out ... I use the word kicked out because they had been treated badly by being removed from there. They would be sitting along the wall, in the corridors, smoking, you'd see these blokes with bits and pieces missing and it became common place and they were a good laugh, "How you doing, boy?" And you'd get sweets and stuff, good as gold, because they were the same age as my dad and they were lovely people, lovely blokes.

And they had a reconstruction unit there, they had a burns unit there so you'd see people ... one particular case we were all sort of stunned by, somebody was having his nose rebuilt so he had a skin graft from his stomach to his nose that looked like a huge trunk. And you'd see things like that as a little kid. I had a little friend there who'd fallen in a fire so he had no face, he just wore this plastic mask. It sounds horrific but none of us were ill so we had a great time.

My mum told me of a story when ... because there was about five or six of us there originally, in the mornings they'd sit us on the little pots in the corridor. We'd all be sitting on the pots, it was at the height of the Beatles and we would be singing all the Beatles songs on our pots and because we were at the bottom of the officers' ward, word came down to Sister Mears, who was running our ward, to keep the children quiet as we're trying to rest. And, this is what I've been told, she stormed up there and she explained our situation and from then on, regularly, we'd get sweets and boxes of chocolates and no complaints, they were as good as gold.

Sister Mears, I think, is the sister that Claus Newman talks about as being extraordinarily good and compassionate.

She was, unbelievable, yes. Unbelievable. She was the matriarch of the ... she was more than a sister, she was the one, sort of thing.

Yes and she took some children home and things when their parents couldn't look after them.

Yes, I remember her taking home a little girl called Tina who'd (better not put this in the book or anything) but basically her parents didn't want to know and she felt so sorry for her she took her home herself and basically brought her up, you know.

No, I've heard amazing things about her...

She was very much old school, didn't do things by the book ... done things that had to be done, needed to be done, not filling out forms.

That's exactly what Claus Newman, when he gave a talk at the Wellcome he mentioned her by name, you know, and said if it wasn't for staff like that all of those young Doctors wouldn't have coped, you know.

No, no. And she was a single woman, no children, and I think she took us on as her children, really. Yes she was amazing, totally dedicated.

I suppose one final question to ask about this early part as well though is... your parents... are they both still living, I think you said your father had died?

No, my Dad died about four years ago.

Right. So we'll talk about that in the adult part ... but your Mum is still alive?

Oh, very much so.

And you still see her fairly regularly?

Yes, at least once a week. She lives on the other side of Swindon. We take her shopping and things like that, so does my sister. So we make sure she's okay and everything but she's what we call a born-again teenager.

Really?

Yes.

So anything further about life until the end of the teens?

No, that's really it really.

You might think of some more things later or when I send you the transcription as well, so...

All right ... okay.

Do you want to take a break now?

Yes, if you want to.

We can go straight into adulthood or we can take a break first ...

It's up to you, I'll probably have a cup of coffee if that's okay?

Yes, let's have a little break.

So you were just telling me about sense of humour in your family and a joke that you used to play in the car.

Yes, when we used to drive down to London and my dad had an estate vehicle ... when he would fold the back down so the three of us, my brother, my sister and myself would just roll about in the back. And we'd get bored with this so we'd entertain other drivers. My brother would either put me up his jumper so my head would poke through and his would disappear so you've got this little tiny head with a big body or he'd put his coat on me and hide behind me so I was swamped by a huge coat and he'd put his hands through, which was huge hands up against a little body and then he'd do things like scratch my eye and pick my nose and how we didn't have other people having crashes is unbelievable.

What sort of reaction did you get?

Mostly people would laugh, absolutely laugh and follow us, sort of thing. And we'd do stuff like that and it was just taking the Mickey out of the disability really but in our terms, on our terms. Yes, we'd do loads of things like that.

My brother thought it was funny to roll me down a hill if we were outside but he always looked after me, you know, if anybody... he would do things but if anybody else, then he was there, and we'd just muck about just like normal kids.

Are you still close to them now, your brother and sister?

Well, my brother died twenty years ago but yes, I'm still close to my sister.

How did your brother die?

Brain tumour. Yes, it was just after I got married, he was my best man, and he was going through a rough patch at work and we thought he was being stressed out because of that and I went on my honeymoon and while I was on my Honeymoon it was his birthday so I phoned home and found out that he had a biopsy and then when I got back found out that it was cancer so ... he died three months after I got married.

Gosh, so he died quite soon after being diagnosed then?

Yes. It was very quick, unbelievable.

That's sad.

It was quite sad seeing him in hospital because he'd always been ... my Mum ... my family is divided; my Dad is the reader, the philosopher and my Mum was the sporty person and my brother took after her and he was the type that if he was playing cricket he's go and get all the gear. Whatever he took up he got all the gear and he played it to his best so he was quite a big bloke, quite a bit strapping bloke, and then the cancer just took it away and he became this frail little old man, hair falling out and it was sad to see, it really was sad to see. It's not the way I'd like to go. If I found out I had anything like that I'd want to be topped.

I suppose you've always got that hope that something might come along and ...

It was too late, it was too riddled in him that there was, you know, after trials and tests ... five or ten years there's no way so yes, that was about twenty years ago. Sad time but we all survived it and got on.

Okay, let's take our break now.

Right.

Okay, so this is the second part of the interview now and we're going to talk about early adulthood, further education, career, relationships, that kind of thing.

Did you go on to Further Education after school?

I did yes. I went to Hereward College which was for the disabled ...

How do you spell that?

H-E-R-E-W-A-R-D. It was strange really because I was leaving school ... I was encouraged to stay on until the sixth form which I didn't want to do but I was encouraged to do it because they didn't know what else to do with me, you know the Councils, whatever, people didn't know what to do with me so they encouraged me to pad out another year, which I hated and hardly attended really, just to make it easier for them to search around for something.

Then they came up with an idea that I go to this college. Now I wanted to go, like yourself, to an art college ... back then accessibility to anything that I would deem to be a proper college wasn't around so they lied to me basically, they said, "Hereward College has a very good art course." I read that as being it's an art college and I went up there, I done my first day assessment, stayed overnight, which was initially weird because I'd never met ... I was seventeen at the time and I'd never really mixed with disabled people so it was the first time, so that was a bit of an eye-opener. And I survived the night basically, with people helping me who weren't my parents, which again was strange, but okay. I mucked in and got around it ... they didn't really go into much of what the courses were, because I was only there for the day, so still I assumed I would be doing art and then I said, "Okay, I'll sign up for that, looks okay," it was in Coventry so I left Stevenage and became a boarder at Coventry and the first week there they said, "Okay, what courses do you want to do?" So I said, "Well I'm here to do art." "Yes, okay, art, now you have to do another seven courses." I said, "What do you mean, another seven?" and they said, "No, you can't just do art." I said, "That's what I'm here for" and they said, "No, no, no ... that's not what it's about." So I had to re-do history, English, maths, all the stuff that I'd done at school, all the things I'd got exam results for again.

At exactly the same level as you'd already done them?

Yes. So I'd got it into my head ... because it was ... as I say I was seventeen, it was back in seventy-seven, it was the time of punk and rebellion and everything, I'd come from a normal school which was full of rebellion and I said, "Right okay." I thought to myself "Okay, you've lied to me, I'll lie to you." So literally I would turn up for all the classes, literally I'd do nothing and the only one I did was art and come the exams I failed all the exams but the art one. But it wasn't enough and they ... it was one of the reasons why they kicked me out after a year.

So was this the first time you'd left home, actually lived away from home?

Yes.

And so how long were you there for?

A year.

One year.

I should have been there for three years but, as I said, I got kicked out after the first.

And what qualifications was it to get then, was that O-levels?

All O-levels which I'd already got at school.

And what did you do after that?

I still pursued my art interest and so I done an Open University course. Again, very misleading. It was basically... art to Open University is literature and furniture and not very much about art itself so it was a mixture of ... I found it too dull, basically, it wasn't what I wanted to do so I gave that up and went on to ... then I had a home tutor for art which I carried on doing and again I got ... I got right to the end of getting a qualification with her and, typical of my luck, my art teacher goes blind.

What?

Yes, which is really weird so she had to stop and that was it.

And so were you living back at home then, with your parents when you did that?

Yes, I was back at home, yes.

I mean my college social life was fantastic because as I say, I had just turned seventeen and I had a raucous time, we were out drinking, me and few mates that I made there again... [Ed's wife brings in drinks].

Enter stage left, right ...

I absolutely had a ball at College. I was young, I made some friends who'd also gone to normal schools and were thrown in the deep end with disabled people, so we sort of grouped together. I mean, it was hysterical, in a way, there'd be disabled kids there that had obviously been either in homes or very, very nurtured at home, at least special schools, who would turn up with brand new denim jackets with patches on and I couldn't relate to that. I thought you only put patches on once you'd scuffed the jacket and they were all trying to be hard and they... because they were second year students, a lot of them, they were pushing us first year students around. And I'd already just left a school that I couldn't stand by this time being pushed around by blokes who were, you know, six-footers and fit, there was no way I was going to stand for it with somebody who could just about talk, in a wheelchair. So I heavily rebelled against that and so me and small clan stuck together and we went out drinking, partying, had a good time.

And were there other thalidomiders there?

Not at that time, no. I think I was the first one to go ... to go to Hereward.

Probably because you were that little bit older as well.

Yes, yes.

So living away from home was good the first time round?

Yes. I had a great time.

And did you have any kind of ongoing health concerns or medical interventions at that time or were you still fit?

I haven't since the age of fourteen.

So you were lucky.

Very lucky.

Yes. So you came back home and you did your Open University course and did you at some point try to find a career or a job?

Well, while I was at college I had a careers officer come round who offered me a job and he said he knows of one going that involved painting tiles, you know wall tiles, floor tiles, which I found as bit of slur at first but I thought, "Hey ho, you know, I'm not Rembrandt, I've got to start at the bottom." And I said, "Yes, fine. I'm interested" and I said, "How many years do you have to be there before you can start designing the tiles?" And he said, "Oh no, you'll never design a tile ... there'll be designers and you'll always paint them," which to me is painting by numbers. And I said, "Thank you, but no thanks," and as it turned out it was a disabled workshop, or a sweatshop basically. After that I got really disheartened. I was offered a couple of jobs of pen-pushing and I'm so not a pen-pusher, I mean if I have to write a letter I get depressed, you know, I like activity and creativity and to sit behind a desk would just kill me.

At that point I knew ... I'd known for a couple of years that I had enough money behind me if I wasn't stupid that I wouldn't have to work so I never bought anything flash like the ... like some of the beneficiaries did, they bought really flash cars and spent their money. I always kept it low key. I also kept it low key because the kids I was knocking about with in Stevenage ... if I turned up with a really flash car and they're driving an Escort I wouldn't stay around for long. So I fitted in with what they were doing, again they were as good as gold, if we went to the pub ... I was never one of those beneficiaries "Hey ho, I'll buy all the rounds if you be my friend." I'd buy my round, they'd buy their round, we'd get on, and that's the way we lived.

And you still carried on living at home at that point?

Yes. I was still at home, yes.

And so who were these friends in Stevenage then? How did you know them? Were they old school friends or...?

A couple were old school friends, one was a family friend who I'm still in contact with to this day, and then I made a few friends because I was on CB, so you make a few friends there and, you know, it just spreads like that.

A lot of people have done CB radio actually.

It's another way of hiding behind a screen.

Yes. Yes. That was the breaker, breaker thing wasn't it?

Yes. Sad [laughs], very sad.

Probably very good fun at the time though.

Oh it was magic at the time.

Okay. So I'm not going to ask you any of those questions about having a job.

What about contact with other people affected by thalidomide at this point. Were you still ever going to events put on by the Thalidomide Society? Were you going there or Thalidomide Trust holidays ?

I never went on a Thalidomide Trust holiday. Again, like I told you before, I've always been cynical and I'd hear stories that ... I don't know if I was rebellious or just an angry young man really but there were people of my disability group that would go on these holidays and after week one the helpers who'd been paid for by the beneficiary, got tired so they'd start putting them to bed at about six o'clock and other beneficiaries would have to help them and to me there's just no justice in that, you know, you pay your money, you do your job and there was no way I was going to fall into that trap.

So in terms of having any peer support from other thalidomiders at that point, were you still in touch with any of those ... ?

No not really. Yearly at AGMs meet up, then I think when I was about nineteen the hotel in Jersey was formed and I used to go there every year because again it ... it probably sounds weird, a group of disabled people all under one roof, but it was so fun.

It doesn't sound weird at all it sounds ... everything, everybody's told me about that...

Surreal times, they really were.

Yes, people have said it was surreal but also you sort of don't have to explain yourself to anybody, do you, because if you know you're all there for the same reason, in a way ... ?

Exactly. The only way I can describe it is ... because we were all roughly the same age, give or take a year, thalidomide people, and I'll probably be criticised for this are really different from other disability groups. We have an arrogance, we have a forthrightness, we have a go-get type attitude, we don't sit back and expect things. So if you can imagine a hotel of about fifteen of us, all with a drink problem, it was two weeks of just sheer mayhem and it was great.

And where do you think that ... this is something that other people have said as well about thalidomide being different from other disabled groups, what's your theory behind why that is?

I think because we were all grouped together from a very early age, although we didn't mix with one another constantly, when we did meet up it was like the time hasn't passed. I don't know, there is a certain arrogance and bull-headedness amongst our group, you know, "We're here, if you don't like it, tough on you" type of attitude and it's ... I like it, I like that type of attitude but many don't.

Have you come across any bitterness of negative attitudes towards thalidomiders getting compensation when other disabled groups don't?

Oh yes, yes definitely. Some has been in print in a magazine called Disability Now, years ago. There used to be the odd article from other disabled groups about our group, that all we think about is money. Oh yes, other groups aren't too happy with us and I can understand it, you know. They're born disabled, they have the same hardships we have and they've got to rely on the state whereas we've been compensated and, you know, they hear us moaning because we haven't got a Maserati or a Ferrari, you know, "Why can't we have one?" and they're going, "Why can't we have a car?" So I can understand them, totally, you know. It is quite unfair.

But the origins of a disability caused by thalidomide are so different aren't they? So it's what Martin always calls a man-made disaster, doesn't he?

We have someone we can point our finger at, they don't.

Relationships.

[Laughs].

He nodded sagely. Did your impairment affect your ability to find a partner?

No. No, not really. I would say my first real girlfriend ... looking back I bamboozled her to go out with me and that lasted a few years and just fizzled. Then I was in the wilderness for a while, then I picked up with another beneficiary.

Was your first girlfriend a beneficiary?

No, no. She was at school with me. I had a little girlfriend as well when I was at infants but I don't think that really counts.

You can't count that.

[Laughs] No. So I picked up with another beneficiary, that didn't work out, on my part. Then I had a dalliance with another one, a beneficiary, that was definitely not going to work out because we both agreed to that, it was more of a one night thingy. Then I picked up with Geraldine who I met at an AGM and after about three years we got married, another couple of years after that, a few years after that, we had two kids.

Tell me a bit more about Geraldine though, who was Geraldine then? Was she a beneficiary?

She is a beneficiary, yes. She's got nearly full length arms and short legs like myself, you know, flipper feet.

So she uses a wheelchair as well?

Yes. When I first met her she was using a push wheelchair ... again, I said to her, "Why the hell are you doing that it's putting a lot of strain on you?" So she eventually got an electric wheelchair and, as I say, I moved in with her pretty quick ... because she was living in Mansfield at the time and I went to stay with her a couple of weeks after the AGM and then that was it, we were together then. She moved to Swindon, got a place, moved in there with her, then we got married, then we had the kids and then she divorced me. I can't understand why ... [Laughs]. I think we were married about fifteen years and she said she'd had enough [laughs] and I was divorced.

First of all, when you got married to Geraldine was that then the next time you moved out of your family's home? After you met Geraldine you moved in with her?

Yes. I moved out.

And how easy was it at that time to sort of adapt a house for two wheelchairs?

Initially, not too bad, the only reason we moved from the place we had in Swindon was we wanted children and it really wasn't possible to have two wheelchairs and a child although we did have my eldest there but he was about one and a half when we moved into a barn conversion and then about another year and a half after that our second came along.

And did you get some help?

Yes. We got home help because that's what the council do. You know, you've got two small kids but we can clean your cupboards, but very understanding home helps, they understood what was needed so they would help with the kids and do a bit of cleaning, that sort of thing, so that was good.

So you said you had two boys ... actually you said that to me off the tape, not on the tape, so when you got to that point of time when you had two crazy little boys running around and you were both in wheelchairs, was that difficult?

Absolutely not, absolutely not. I find with all the beneficiaries' children, they are amazing, they don't adapt because they're born into it but I noticed ... I haven't noticed any not being very caring, very helpful, very understanding. When I say helpful I don't mean they are slaves, because a lot of people think that you have children as carers. But they are not, if they don't want to do anything, they will disappear. But it's second nature, if I drop anything, one of them will pick it up automatically, just pass it to me, without even thinking.

From an early age we knew that we were going to have trouble, we couldn't chase after them if they ran off, so voice control was very important. Geraldine trained the boys to hold onto her wheelchair, which they did. My youngest still does now even without thinking. If I'm going down the street, he'll hold onto the back of my wheelchair because that's the way he was trained to do it.

But they're as good as gold, they automatically open doors ... but I find that with all the beneficiary kids, they're really, really good kids.

And did you have ... or was it suggested to you at any point that there might be a genetic inheritance from thalidomide that might pass onto the children?

Yes, there was a rumour going round but I'm too practical for that. There's no way our genes were altered, the embryo was altered, not the gene. So there was no way I was worried that it was going to be passed on. I remember going into the ... you know, when Geraldine was being examined and the nurse said to me, "Oh, the baby's got long legs." And I thought, "Well, I was expecting that." I wasn't expecting sort of a penguin or anything, you know.

I used to wind them up ... I loved watching people's faces. They used to say, "What are you hoping for?" meaning boy or girl. And I used to say, "Spina bifida" because I said, "We've already got the home adapted, it would be ideal." [Laughs] and they were horrified by that.

So nobody tried to, in the medical profession, tried to persuade you not to have children because you were a disabled couple?

Oh God, absolutely they did, because the thing is, it's going to go in the book, I fire blanks, always have done and so the children were conceived by IVF and to go through that when you think that any chav girl of fourteen can have as many kids as they like, nothing's said. We had to jump through hoops, we had to be investigated, we had a social worker come to our house to see if we were fit to be parents and she ... we ended up having to pick her up because she lost her car keys and therefore we had to pick her up at the station because she didn't know what she was doing and I thought, "You're investigating us and you haven't even got your life sorted?"

Yes, we had to do a lot of that and we were refused ... I think he's died now, some bigwig genetic Professor in Bristol who said no way should disabled people have children. So again, because of who we are, I said, "No way, that's not going to happen" and we just carried on.

Geraldine wanted to adopt and I said, "The chances of us being able to adopt is very slim" being that we don't fit the criteria of middle class white people who go to church. I said, "It's not going to happen." So we went for IVF and after eleven attempts, Charlie came along and to this day I've said, "When he turns eighteen, he's not going to get a Birthday present, he has to pay me back all that money," which he still sobs about [Laughs].

So how long did eleven attempts take?

Over a year, well over a year. He was actually conceived on my Birthday, we'd almost given up, we were going to try something else. And I said, "No look, we've already got it booked, let's go, let's have a shot at it." We did and we were ... we spent the weekend away with my Mum and Dad down at Dorset so I had to drive from Dorset up to Oxford which was a long haul. I was really tired when we got there, she had the treatment and he was conceived.

Fantastic, and then going through the pregnancy and the birth, did you encounter any other sort of, you know, have you encountered people thinking that you couldn't cope, basically?

Oh yes. Yes, all the way through. You'll also get ... you know, Geraldine would be going round the streets as a proud mother with Charlie, the eldest, on her lap, totally safe, I mean, we're disabled, we're not stupid, you know, we don't want to drop the baby, totally safe, and you get strangers coming up saying, "Let me have a look at your baby" and literally taking the baby off of her, thinking that we were, you know, part of a circus act and that you can just take babies off of these people and you get a lot of that. You know, the baby's not safe ... this, this and that. It's just through ignorance really, people just don't understand, don't want to understand.

No, no. I think it's probably as well because people aren't able to imagine that if you're in a differently shaped body you're still able to do things they somehow put themselves in that body and think, "I'd drop everything," you know.

I mean I used to carry both babies with their baby grows on. I'd bite the front of their baby grow and just lift them up with my teeth and carry them around, supporting their heads obviously, they were fine, right as rain. Then I had this harness fitted on the front of me that I used to carry them around. But in the end what I used to do that was the easiest was, I would sit them on my leg, I would turn my foot so that would support the babies bottom and I'd hold the collar of them there and they'd sit there and I'd take them round the street like that, they'd sit under my coat and just have their heads popping out and they'd be fine, absolutely fine. Well they're still here today so it worked.

Well yes, that's a good testament isn't it?

Yes.

And when you came to send your boys to school, how did other parents react then to you being ... did you still have that same thing where people thought, you know, as a disabled parent you wouldn't ... ?

No, not really. It was suggested that one of us go up to the school to explain our disability. I left that to Geraldine because I'm not good at that, I'm not good at telling children the truth.

Oh I see, to speak to the class you mean?

Yes. I mean, when I explain my disability I go off into the realms of fantasy because I don't think kids want to know the truth, they want to hear the romantic side ... tell them I'm an alien or whatever they ... or if their eyes light up I'll carry on with that, you know, "Why should you be burdened with the medical facts? That's boring, let's have a bit of fun here." So I left that to her to go and do the Mother Nature bit, you know.

And I mean some of the kids did ask the boys about us, the boys spoke honestly, as they do, and they've still got all their friends from infants and I know all them and now they're all big strapping six-footers but, you know. And it was lovely going up the school when ... some of the little kids, I mean you're talking about four / five year olds rushing to the door to open it for me, "Hello Mr. Freeman" and open the door and, "This way," and they were good as gold, lovely kids.

And did your sons ever feel affected by anything anybody said about you when they were at school? Did they ever feel embarrassed or...?

I think deep down there were a couple of jibes made at us which they didn't like but overall I've taught the boys ... my philosophy is, I'm not always going to be around, "I am going to die at some stage so you have to develop a thick skin and either put up with it or fight back," and they do that. I mean not in an aggressive way but I don't want them to be bullied or anything like that so they're quite strong characters and quite surreal characters.

What are they like now, your two boys? How old are they?

Eldest is seventeen, youngest just turned fifteen.

And do they live with you or do they live with Geraldine?

They live with their Mum but I have them most weekends.

Right. And at this point of time ... because I know you were saying that you decided you didn't need to go and find a job, but were you still doing your artwork at this point?

No. I became quite deflated and to be honest I was side-tracked by CB and having a good time so I had my own personal gap year or two.

It was only ... I think my brother saw I was wasting my time and he was working for a computer firm at the time and he said, "Can you make ... we want some cards for a meeting we're going to, could you do a cartoon? I'll give you the line, it's not a funny line but we know what it means, you draw a picture for it." And I done a pen and ink drawing for it, it was turned into a card, it was appreciated which I didn't really care about, you know, I didn't want adulation but I enjoyed doing it. So then I thought ... and it got me back into drawing and I started off with pen and ink outline drawings of ... I chose thalidomide characters because I thought, "Nobody can have a go at my drawings about thalidomide people because I'm thalidomide," you know.

You've got the automatic right, haven't you?

Yes and it's a good little niche and it's a cop-out, you know, I've got no competition. So I started pushing these around and some of them got sold and taken up, took a long, long time, then ...

Sorry, just to put this in the timeline of things, was this when you were married that this was happening?

Yes.

... and after your children had been born?

Before. Before the kids.

Then, because I work so close, because of my reach, my eyesight started to go so I needed glasses and then the pen and ink drawings weren't as good as they should be. Then home computers, proper ones, not ZX 81s that were just toy machines, but proper computers came in so I started using them to draw with and then as the technology went along, got better and better, I switched from pen and ink completely over to computer graphics, which I do today.

Okay, so that's been ... how many years would that have been? So the computer graphics side, would that have been after you became a parent?

Yes.

And what do you do with your... mostly what's your favourite subject matter for your artwork and what do you do with the pictures once you've done them?

My main passion is I've always loved Frank Rosetta sort of the comic character, you know, the big muscular bloke, the voluptuous women and the sort of Thor look. I've always liked him, I've always liked Salvador Dali, so most of my stuff is like that. I was told by another beneficiary who's properly into the arts side of things that I have very much a comic strip style so at the moment I'm trying to sell them but my main ... what I do regularly is contribute to Disability Now magazine so the cartoons in there every month are mine.

And how much do you think you spend of your time doing art now?

Far too much [laughs]. Far too much. Ask Claire.

Okay, go on, give me a rough idea and I'll check with her afterwards and see if agrees.

Oh God, some days it can be all day, other days, three or four hours, but too much really. But I just love it, I just love it.

It's not exactly wasting your time though is it so...

Can you tell her that? Can you tell her that?

Yes well, it's better than if you were watching TV for four hours.

Exactly, that's exactly my thought. And I'm learning all the time because ... because I post things online other CG artists see my work, they don't even know I'm disabled and then we have forums that we discuss and "How do you this?" "How do you do that?" So you're learning all the time, it's great.

So it's a kind of a social thing as well?

Not too much, no. I wouldn't meet up with these people.

No, but a little bit.

Yes. I get information and, you know.

And so you very quickly passed over your relationship breaking down, you know, "We got married, we got divorced" ...

Yes.

So what went wrong? Why did you get divorced after fifteen years?

It ... again, I say fifteen years probably about five if not six years beforehand things weren't brill. We were just living it, two strong characters because she's, you know, a thalidomide beneficiary ... two very strong characters both evolving. She was evolving more than I was and she wanted more out of life than I wanted and one day she just said, you know, "Enough's enough." I wanted to stay together probably for the wrong reasons of, "But we've got two kids," you know, "My family don't divorce, we've got two kids," which isn't probably what your wife wants to hear. I think she would have preferred me to say, "No please don't go, I love you so much" and I just went, "No, we've got two kids" and she just went, "Right that's it ... over." And basically then I thought, "That's it, it's dead and ..."

How long ago was that?

Probably about seven years ago, seven, maybe a little bit longer.

And my philosophy in life is onwards and upwards and that is, once a door is shut, you just smash open the next one. So I wasn't going to let that ... it never depressed me to the degree that people worried about me. My parents were worried, they said, "You're happy, you're getting divorced and your happy?" I said, "Yes, I'm happy because there's new things ahead, you know, there's a new life." And of course once you're in a relationship that you don't realise how dead it is until you come out of it and when you're out of it you go, "Jesus, did I put up with that?" you know, it's great, "Let's go and party" and I did.

Did you? Tell me about the partying then.

Done the typical bloke thing, met up with me mates, went out and got drunk a lot, went to nightclubs, made fools of meself, went online, met various ladies, made fools of meself and that was it.

Was it fun though?

Oh, it was brilliant, absolutely brilliant. Recommend it to anybody who gets divorced but it gets boring after a while, it really does and it's funny, I got divorced at the same period as a couple of mates of mine done, did, and we all went through the same phase and then bit by bit we all sort of woke up and go, "This ain't as much fun as we thought it was." And you go, "No, I want to sit in and watch telly, I want to do boring

things,” and then you know, while online I met Claire. I told her ... didn't tell her at first I was disabled but I told her I had kids because to me that is most important, if you can't accept my kids then let me know it won't go any further and she already had two girls, very close to her girls so I thought, “Well, she's a good Mum, that's always a good sign.” She knew about my two, we met up and then I told her I was disabled I said look, “I'll break you into this” and she said, “Well,” typically, like everybody does, “That doesn't matter,” but of course not. We met up, she was a little bit shocked you know, you can see their faces, but after twenty minutes, half an hour, like, no problem.

So the first time you met up with her you met up with her and her daughters?

I met up with her first.

Just her, yes.

Just her, yes, and everything went well. Then after a couple of meets I met her daughters, I took my boys over. She was living in Bristol so we were going ... swapping backwards and forwards. We'd all make ... because we're family orientated we'd always make sure that I left after the boys had gone to school and was back before they got home from school and she would always pick her kids up from school as well. So we fitted it in and it all went well ... at this point this is where it sounds really weird, because I was still living at the barn, separately ... because of the nature of things I can't just move out and go into a bed-sit so I was still living at home, waiting for Geraldine to either pay off my half or we sell the place and split.

And she'd actually physically moved out?

No she was still there. That was a lot of strain at that time to be honest because Claire was coming to visit, she'd already... probably off the record, she'd already picked up with a bloke before she let me know she wanted a divorce so there was all that going on as well. We tried to make it as easy as possible but it does get difficult.

So then finally she said, “I'll keep the place because the boys have grown up here,” and I thought, “Yes, too right, you've got the bigger place.” So she kept the place, she paid me off, bought this place, having it adapted, I said, “Claire do you want to move in?” I don't even think I said that ... I don't think either of us actually made the decision, it was just automatic that she moved in, moved the girls in and then we lived here for about a year while it was being adapted. We was in a room which was an old dining room which was probably about eleven foot by ten which we had a bed in, a wardrobe in. I had to have a caravan toilet because they had no special toilet here and we were like that for coming up for a year and that was really difficult and I thought, “If you can make that, you can make anything.”

Yes, yes. And Claire for... I mean I've obviously met Claire because she made me a lovely lunch but for the tape, Claire is an able bodied person.

Yes. Well, she calls herself that, yes. I let her get away with it.

And were you the first disabled partner she'd ever had?

The first physically, yes. By the sounds of it she's had a few sort of off the wall ones but yes, I was the first physical one.

And has she ever talked about how she... I mean it's a new situation to go into, isn't it with somebody? Did she have like a lot to learn about you and a lot to learn about the things you need that beyond ... ?

Yes. It's not something ... you just don't go, "Here's a list of things that I need." It grows over a period of time and she'll see if I'm struggling or if I need help or anything and she'll do what's necessary. I mean, she's not a saint, nobody is and there are times when she's busy and cannot get there right that moment, which is fine, I mean, as I say, my Mum was the same, you know, this is reality but nine times out of ten, yes, good as gold.

And what was it like living with somebody else's children?

Different, different. Because the girls had been brought up in a normal household voice control wasn't there. I might have that put in later actually so ... plus they're girls and I've got boys, you know, so I'm watching the telly, watching a western, or sci-fi and they're sort of watching Take That and so the culture difference was huge but over a period of time, yes, we're coming together.

And you've been together for about four years now?

Six in all.

And you've lived in this house for most of that time?

Yes, most of that time.

Yes. And what about the two girls moving in to a home where you have to make adaptations and things, do they just take it in their stride?

They take it totally in their stride, totally. If there is any arguments, I mean it's a normal household, if there is any arguments it's never about disability...it really isn't an issue. And they do things like ... they get angry on my behalf, like if they see anybody who shouldn't be in a parking bay, using a parking bay, they get really angry and they get really angry about certain disabled issues because I think they can see the other side of it now. So yes, they've adapted really well.

I'm not going to ask you about health concerns or medical interventions because you haven't had any.

No. Oh, I've had one. Sorry ... two, but nothing to do with thalidomide.

Go on, what are they then?

When I was nineteen I was in a car crash ... no eighteen I was in a car crash and I went through the windscreen and all underneath my chin and my neck was cut open and I lost sight in ... well, I didn't lose sight but part of it was damaged so it's completely blurred. So that was when I was eighteen and then about seven years ago when Geraldine and I split up and you start going onward and upwards, by then that eye had got a cataract in it and I was literally blind in that eye and I thought, "This is wrong," so I did go to a doctor and I had an operation and had that cataract removed, and then I wear ... I'm supposed to wear a contact lens in it but I don't often.

It's just a very slightly darker colour isn't it?

Yes.

Or is it the pupil that's larger?

It's the pupil.

It's just the pupil isn't it?

It's exactly the same thing as David Bowie's got.

Oh does he? I always thought he had one green and one blue or something.

No, it's open.

You've just reminded me of one thing I was going to ask you about as well was you were going to tell me about being a bit punky at a certain point of time with your clothes and your ear piercings and your tattoos.

Yes, I don't know if it was nationwide but certainly in Stevenage ... I think it was nationwide actually, we went through ... coming out of disco, hit punk and then all of a sudden all these various groups sprouted up like there was the return of rockabilly, teddy boys, ska was really at the front. So there was a lot of groups going on and in Stevenage, which is just north of London, they seemed to adopt the London way and there was loads of groups and I didn't know which one I liked so I just joined them all, one after the other and so one moment I'd be wearing a dog collar the next I had a drape and then I had a black and white pork pie hat and stuff like that.

And what about your tattoos, what have you got ... you've got one... ?

[EF and RB look at EF's tattoos] That one is bad because I was drunk and that bloke who done it wasn't much better.

Okay, and when did you get that done? How old were you?

My mate bought it for me, bought both of them, as a twenty first Birthday present. That's what it should look like ... it should be a swallow with a flower underneath.

Oh okay, it's more like a swallow with a flower sort on the side isn't it?

Yes, yes.

But it still looks good. Why did you have a swallow with a flower?

Well, I wanted, because I'm ... my birthday's in August so I'm a Leo, I wanted a lion's head but the only tattooist I could find that could that would, not could... the only tattooist I could find really, was again in Hitchin and he worked out of a shed in his garden and when me and my mate went there, he had his done as well, he asked me what I wanted and I said, "A lion's head." He said, "I don't do lion's heads," and I'd already had a drink or two by then and it's full of skinheads and retrobates and oh it was awful ...

[Laughs] I'm trying to work out how you get from a lion's head to a swallow with a flower under it, but, you know...

Yes, I know. So he said, "I don't do that," and there was no way I was going to back out so I said, "Well what do you do?" He said, "I can do a swallow." [whispers] "Do a swallow" and that was it.

[Laughs] And then you have it for life.

Yes and that's why ... my eldest son, he wants a tattoo and I said, "I don't mind you having a tattoo," but I said, "I'm going to be there with you." And he said, "Okay." So I'll be with him so if he's out of his trolley or whatever, I'll go, "No, not having that" [laughs].

[Laughs] And your ears pierced?

Well, I had both the tattoos and the earrings for a reason. It wasn't just because it was the style of the time, although it was, but I wanted to make a statement that, "Yes I'm disabled but mentally I'm not." So I went

and joined in what everybody else was doing. So I had the ... first of all I had one earring done then I had two in one ear, then I had the other one done at which point my brother even called me a poof for having both done and then I split up with Gerry so I thought, "In for a penny, in for a pound," and I had the other one done so I had two in both sides, then I had trouble with the earrings, had to take them out, so I just put in one in either side.

That's an interesting point that you said about, you know not wanting to shy away from going through the same fashions as anybody else is at the time, if that's what you want, obviously, you don't have to do the same.

Yes. Where I was, all the kids all had earrings, all had tattoos.

Can I ask you a little bit about technology as well, like the ... it's slightly different in your case because you used the prosthetic legs for a long time, but I know other four limb deficient thalidomiders have said that the first wheelchair was, for them, like the first moment they really gained independence and the car, having an adapted car, have you had similar feelings about those kind of things?

Yes. I'd agree on both those cases. Going from legs, which was quite restricting...I mean it's great standing up, still ridiculous because there's no way I was the same height as everybody else, but I would stand up, into a wheelchair that I could then go out into the street, down the street, back again, you know, something I could never do with artificial legs. So yes, it was liberating, yes, very much so and then getting a car so I could go wherever I wanted, yes, it was great.

When did you get your first car?

When I was eighteen.

And how easy was it to get it adapted at that time?

I think it wasn't that difficult. I bought a second hand car that had already been ... belonged to a disabled person because it wasn't ... no one was sure if they'd be able to adapt if for me, and it was Daf 44, that's the one I had the car accident in. And it was quite...it seemed at the time quite easy to adapt. I wasn't able to get in and out myself so I had a push wheelchair at the time which either my parents would put in the back or my mates would. And then going through that stage when custom cars were at their height, I had the furry dashboard and the furry steering wheel and all the other old tat that goes with it.

Did you have the hanging furry dice?

No. No, I did stop there. I did stop there.

Is there anything about how your feelings about ... this is a difficult question to ask and to answer, but over the years how do you think your feelings about your impairment and the thalidomide story have changed? Do you think you've gained any kind of strong insights or feelings about it?

It's not something I've really thought about. You live life. It's not something you analyse every day. It's like saying, "Why have I got black hair? Why am I blond? Why have I got blue eyes?" It's there. You are what you are.

I would say society has changed a hell of a lot in the fact that getting around is a lot easier, adaptations to buildings are brilliant. I'm no longer a fire risk if I go to a nightclub or a pub. I get annoyed when young disabled people keep decrying what they can't do and I think back, you know, you've got it all. Why are you moaning? You know, that's the only thing that gets me.

Were you ever interested to learn about the history of the production of thalidomide?

I'm very interested in the connection with the Nazis, very interested. To try and understand how short-sighted they were that this would never be found and what kind of monster mentality would release that on the general public. Are they deliberately trying to wipe people out? They couldn't do it in the gas chambers so are they doing it genetically or trying to wipe out a whole era and it's really weird. Why would they do that? And it's nothing about the drug ... well, there's a few things, it's good for cancer and stuff like that, but it ruins the nerve endings of people and it wasn't just the creation of us kids but a lot of elderly people died through it. You know, it was not, and is not, a brilliant drug, especially unsupervised.

Yes, Claus Newman, when he was talking at the Wellcome the other week, described it as toxic.

Yes and what was in their minds to release that? And, you know, I'd like ... because there's talk about trying to sue Grünenthal and I would love to bring them to their knees. But I think any company that works with a Nazi mindset is not going to give in and no way will you ever beat them. They're not ... you can only challenge them if they've got some more output or ideology. You're not going to beat them, it's like fighting robots. They don't care and people who don't care will just brush you aside.

It's very difficult, isn't it, that side of the drug industry? Looking back over your life, from the point of view of today, is there anything that you would have changed or done differently?

No because I think everything you do is an education whether it's good or bad. If you learn something from it, it's a good thing. If it's bad what you've learned, then don't repeat it, simple as that.

That's a good philosophy to have. And in terms of health now, is there anything that you've found has changed? Are you getting more pain or are things changing as you're getting older?

You're going to hate me, no.

No, well, I wouldn't hate you for that. I'm really pleased for you. It's just that a lot of people seem to be getting more pain now, wear and tear ...

Part of me ... it's weird. A large part of me is lazy. Another part of me is realistic and that is if you overdo your body, your body will overdo you. So I've never pushed my body to excess. I used to go down the gym with a couple of mates and ... but I never exerted myself more than that. As a little child, before my wheelchair days, I used to roll about on the floor and stuff like that. I stopped that, not because I couldn't do it any more but because I didn't want to look ridiculous. So I stopped it because of ... hormones stopped me. I thought, "I'm a teenager, I'm not going to do that any more." So I've never really exerted myself, pushed myself too far.

And from now on, what are you hoping is going to happen next in your life? How would you like to see things pan out?

Well apart from a Lottery win which I don't think is going to happen because I don't do the Lottery so there's a twist in that. I'm probably very much like my dad and that is, you live your life with your family and you just live it and enjoy it. I've got no great expectations. I would love my cartoons ... or not my cartoons so much, I just do them for fun, but I would like my proper stuff to sell. Not because I want the money but because I want something left behind that will say I've been here.

Hence, quite selfishly, I did donate my legs and I donated a headband that we had to wear and my second car to a museum because I thought, "Well, I don't want me or any of us beneficiaries just to be history because then you stand a chance of repeating it." And that's the same reason why I don't want the holocaust to be forgotten because as soon as it is, it gives a chance for somebody else to come along and do it again. It has to be there in the memory.

That's one of the main reasons why we're doing this project as well, to gather the stories so that they don't get forgotten and just lost through time.

I've gone through all of my questions now but is there anything that you'd like to add that you think so far we haven't covered, bearing in mind we can cover things again in the follow up?

Probably little anecdotes.

Go on, give me loads of anecdotes.

From when I was a child.

Yes.

I think it shows the broad outline of how I grew up. My dad, as I say, was a bus driver and when he was on split shifts, sort of thing, he'd be down the bus garage, the canteen, and he'd play cards down there or dominoes. So at the age of sort of four / five, my mum would take me down there while she went shopping

and he ... at the time I didn't like it but he obviously knew that he wouldn't be around forever and he would make me walk the length of the canteen to go and get him a cup of coffee or tea at the time and get him these Club biscuits he used to like. I hated it because I was a little kid and I didn't like to talk to big adults and I didn't like to walk that long journey because I could easily fall over because everybody was smoking at the time and matches were all over the place.

But he made me do it and I'm glad he did because he broke that thing down and he taught me how to ... he said to help me manipulate my fingers, how to roll cigarettes for him, which I could do quite nimbly. I could make three in a minute I think. He taught me, while I was down there, dominoes and cards, and basically I grew up with a lot of adults through the hospital, through my dad at work. My siblings were older than me so I've always ... people say now, "You were born aged thirty five" because I've always grown up with adults and that's who I am.

It's a fantastic insight on the part of your father to get you to do those little things and not to say, you know, if you said, "I can't do it," not to say, "Never mind, you sit down, I'll do it."

No, he wasn't like that. He ... I mean it sounds like he was really cruel but not at all, not at all. He ... my mum stopped him at one stage because he tried to teach me to sit on a dining room chair and then to jump off without artificial legs, just as I am. So he put a big pillow down and then I'd jump off onto it and then my mum did stop him doing that because that was getting a little bit difficult.

He taught me how to fall so that as I fell forward, I'd twist, so I fell more on my shoulder than on my face. Yes, he was more practical, a lot of practical stuff. He insisted that I drove even though my mum's a typical mum, "Don't do that, everything's too risky!" But he said, "He's got to learn, he's got to learn independence." And yet, ironically, it was him that really wanted me to go back home after I got divorced. And I said, "No, Dad," I think I was about forty seven or something. I said, "I'm far too old to come back home. There's enough things out there to help me live independently, I'll be all right." And he was the one who was desperate for me to go back home even though he wanted me to be independent. So it was really weird.

But my mum, she would teach me in other ways like for my seventh birthday she bought me an Action Man, which I really, really wanted. And when you're seven, it's a toy but my mum could also see it as another good thing to help me manipulate my fingers – putting the clothes on, stuff like that. So I was being educated without even knowing I was being educated.

And my sister, when she came home from school, she taught me to read and write. So at five, I could read and write perfectly well and that didn't help with school because I found it quite boring. I could read and write to the degree that, at seven, I was, what they now call mentoring, assisting other young kids in my class to read and write. My brother taught me art and how to wind people up and annoy people, which I love doing to this day, you know, and it was good. It was all good.

So in your story so far, the role of the family and family support has been absolutely key, hasn't it, to making you who you are?

Oh yes. It wasn't just the close family, it was the extended family as well. My mum's sister was working so my mum would look after her little girl who's six months younger than me and we virtually grew up together and there was no problem with the disability. On my dad's side, we used to go down there quite often, if not every week, every other week to London. And I've got loads and loads of cousins and every time I turn Facebook on, another one's been born. Big Catholic family. And I was just another one of the cousins.

I remember sitting ... typical of the family, when you're about thirteen / fourteen, they'd go down the pub and we'd sit in the back of me dad's car, me and a couple of cousins about my age, and they'd bring out a couple of beers for us even though we couldn't drink. And we'd have that and just generally being normal kids. It's good. It's the bigger family and the close family and it's always been solid.

Yes, it sounds a lot like your parents were looking out for you but in quite practical ways, trying to think of things you could do. It's very refreshing to hear.

Anything else before we stop this part, do you think?

Again, it would probably have been my dad when I was in my teenage years, when I was out partying and getting drunk, very drunk, coming home very drunk, he'd always stay up for me and help me because you also get sick when you get drunk. And he never ever moaned. He never ever moaned. All he used to say to me was, "I wish you wouldn't drink so much, boy, it's going to harm you. It's going to harm you, going to harm your kidneys, going to harm your liver ..."

Did you take any notice?

Of course not. And then what finally stopped me drinking quite so heavily is he saw me with a group of mates in town one day and we all had Special Brew cans and he came up to me and he said, "It's gone too far, you're drinking far too much." And I could see in his face he was really disappointed, I could see disappointment and that was it, I eased right back. I still drink but not to that degree. Not to that degree.

No, I think maybe it was a good thing he saw you when he did.

Oh yes, I was definitely on a slippery slope and he just sort of picked me up at that point. I think a lot of beneficiaries do drink heavily and I don't know if that's a physical thing or a psychological thing. I don't know, I don't know what it is.

It's hard to say, isn't it? I don't know that many beneficiaries but it does seem to be a topic that comes up a lot on Facebook. Do you think it's partly pain relief? Emotional pain relief?

That might ... all I can think of ... I don't think it's emotional pain relief, I think it's, again, when they're out with their mates, you want to be the same as your mates so you drink, you can't dance or anything else like that or do all the other stuff so you're left at the bar. So therefore you drink twice as much as they are because they're off dancing, you're at the bar but you want to be part of the thing. And before you know it, a little problem develops and it's ... I mean I've known a good few beneficiaries to die because of drink and they ... the ones I have known to die through it were extreme and I think that was mental pain relief, they didn't have good homes at all and they didn't have anybody to say, "No, don't do it." And it's sad really because they were nice people but there you go.

Could be something to look into in general, try and ... well you said you drank too much at a certain point, was yours just purely social do you think?

It was social, it was to keep up, to be part of the crowd sort of thing. Then, as time goes by, I'm one of those who actually like the taste of it. A lot of people say, "I drink heavy to get drunk but I don't really like the taste." I actually like the taste. So yes, that was it.

Yes, it's definitely something to follow up and to think about, that relationship with alcohol.

Okay, I think it's time to stop here today.

Okay.

Thank you so much, it's been fantastic to speak to you.

Thank you. Have I used as much as Simone? Or is that possible? Who can?

END OF RECORDING

