

49. Kushira Hackett

(1) Tell me about your background.

I was born in 1962. White mother, black father. My mother was of European descent, her mother being English, her father Welsh, and my father was Guyanese, from South America. He had a very mixed upbringing, but that's where he says that he comes from, although there is Mauritian in him as well, and also Bajjian. I'm the oldest of three girls - I have two sisters. At the time of my diagnosis, or just before diagnosis, my younger sister was diagnosed with tuberculosis - was actually hospitalised for three years. So, it was very much myself and my younger sister who were in the house, and it was very strange when she came home; I remember that much.

What was it like being brought up with two different cultures?

Wasn't really aware of it as a young child. My father dominated the family in the household. Being black or white never came into it at all. We lived very much by Dad's rules. He was very strict. He came from a Muslim background, although he wasn't a practising Muslim as such, but we all had to adhere to the rules that Dad set, my mother included, and woe betide anybody who broke them. My grandparents and aunts and uncles used to come round, all of whom were white, but at that time I either wasn't able or didn't choose to make a distinction - they were just family, basically. I think my Mum had a hard time adapting, because, obviously, coming from a working class English background to a man who had very high standards, and was a single man but brought the Caribbean with him, she had to adapt to a way of cleaning, of cooking, of presenting food, of looking after us, and I think it was very difficult for her. As children, we just sort of kept our heads down and got on with it - you were seen and not heard. And he was very much a disciplinarian, so there was... in retrospect I would say an unhealthy amount of fear, but kept us at bay.

You say that the grandparents and relatives who came round were white. Were there any Muslim relatives on your father's side?

When my parents were together, my father only has - and still only has - an uncle, who lives in West Bromwich with his wife, and we would go and see them every week on a Saturday morning. His wife was a midwife, and very high up in midwifery apparently, and her husband was - and still is - a jazz pianist. Plays for a band who's sort of quite famous. There weren't any rigid religious procedures or prayers or anything. In fact, God wasn't mentioned very much in our house, until it was deemed necessary for discipline or for... as a way to sort of press a point. But other than that, it wasn't really used. Only when Dad felt he needed to press a point or to win a point did he bring God into it.

(2) You mentioned "when your parents were together" - when did they separate?

My parents actually separated, as far as I can remember, when I was about five and a half, six years old, so that would have been 1966, '67 time - not long after

my younger sister had been admitted to hospital. From memory, my father had an affair with a woman, whose husband my mother later married! Very complex, but very honourable in the way that it happened. And yes, I was about five and a half, six years old. Dad left the family home. Because my sister had been diagnosed with tuberculosis and we lived in Sparkbrook - which is a very multicultural area, and there was a high proportion of Asian and West Indian families down there - the hospital thought it more suitable if we were moved to a more rural area where the air would be fresher, and there'd be less likelihood of my sister re-contracting the tuberculosis. So, we were actually moved up to the Maypole, where we were the only black family, apart from - fortunately - our cousins, who lived up the road. So, it was good moving up to Maypole. It was bad in the respect of there was a lot of prejudice that we'd never before realised, because, coming from a multi-cultural background, we were just people - we were just kids playing, we never looked at colour. But, of course, coming into a fully white background - especially for my mother, it must have been really difficult as a white woman with three black children - and a single parent to boot. So, community life was very, very different - friendships were very difficult and very strained. So, we became very close with our cousins, who were Muslim, and spent a lot of time there with them, often going up for weekends. And they taught me how to plait my hair and to cream my skin and so on, so forth - things that had been with Dad we would have learnt automatically, but Mom just wasn't totally aware of. She did as much as she could, obviously, and as time went on... well, from day one, she was an excellent mother. You just can't fault her - well, I can't fault her anyway. I'm not sure about my sisters, but I certainly can't. You know, I have to admire her strength of having to walk through an estate full of white people shouting and jeering and twitching curtains with three black children. But she always made sure that we were immaculate. Our hair was always not a strand out of place, our clothes were clean and pressed - if not brand new - but we always looked immaculate. And it was a very difficult time. But being with the family helped, until my uncle died. He died in late 1969 - I think I'm right - late 1969. And then by January 1970, thereabouts, I was taken into a hospital, because I wasn't eating... no, sorry, I was eating, I was drinking profusely, I was urinating profusely, I wasn't sleeping very well, I had very bad tempers and mood swings, I lost an awful lot of weight. And the doctors had been treating me for six months for 'flu. Then, in January, I was taken into hospital. Because I was black, the first thing they thought I had was Sickle Cell, until we proved that there was no Sickle Cell trait in my father's family. They tested me for tuberculosis, because obviously with my sister and so on, so forth. And it was probably about three or four weeks before they found out about the diabetes.

(3) Was there any diabetes in your family?

There wasn't. My uncle dropped down dead one morning - had a heart attack suddenly. He was only in his early forties, and I was actually there to witness that. And they reckon that the shock of seeing that, as well as the trauma of my parents splitting up, in addition to the trauma of having to move area and

fit into a new community, a new school and everything, may have brought it on. But they said they really don't have a reason.

Looking back, do you feel you were traumatised by events?

Extremely. I was perhaps six and a half, nearly seven at this stage, and because it was a Muslim funeral, we were... as children, we had to say goodbye to uncle. And I remember my father lifting me up and forcing me to kiss the corpse goodbye, and I remembered that that was an awful feeling. And as we were walking away from the coffin back to our parents - well, back to my mother - my father squeezing my hand and saying "don't you cry, don't you show me up, don't you dare!", you know. And sort of having to hold it all in, and just remembering the feel of these cold lips and that face so, you know, so up close and so on, so forth. And then, after that - very soon after that, in fact, perhaps within a week - I started feeling unwell. Couldn't put it down to anything. Wasn't able to sleep very well. Mum took me to the doctor's - he thought I had 'flu, so sent me home. Time went on, I was drinking more and more, I was losing weight like it was going out of fashion, and Mom used to notice that my mouth smelt funny, and she didn't know what it was. So, she kept taking me back to the doctor's, and they kept saying it was 'flu, it might be a chest infection. And then I got to a stage where I actually... I think I became unconscious, and my mother called my father, because they were separated at this time, and he came straight up and they took me to hospital. And there I stayed for seven weeks.

(4) Tell me about your time in hospital.

I was taken to the Children's Hospital in Birmingham, which at that time was at Five Ways. And originally... initially they couldn't find out what was wrong, and it took them three weeks to diagnose the diabetes. Thereafter, I was sent to a separate ward - up to a different ward. And I wasn't told about the diagnosis - I was just moved from one ward to another. And then they showed me how to test my urine, by putting five drops of urine and ten drops of water in a test tube with a little tablet, and if it went blue, that was good, but if it went orange, that was very bad. And I knew mine was always orange. But that's as much as I knew: blue was good, orange was bad, but as to what else it represented, I had no idea.

What about injections?

Yeah, they started giving me injections, and I remember that I didn't like them very much... no, in fact, no - the first thing they did was actually put a drip up. I had a drip - I remember that, and then when the drip came down they started giving me injections. And then after perhaps a week, a week and a half of injections, they then decided that I had to learn how to do this. And it was great fun. I had a big glass and metal syringe with a big old needle on, practising on an orange, and it was super. And they said "right, that's good, you've got that down now. Now time to try it on yourself". And I thought "well, why I am doing this? What for?". "Well, you're not very well. You have to take this because it will make you better". I thought "well, I don't like this, it hurts",

but they persisted. And I ended up doing, I think it was one injection a day, to start with, and then I was sent home with my parents. That was as much as I was told. I sort of found out afterwards that my parents had a full teaching. They were told about the food, they were told about my diet, my Mum was given special scales and a book regarding the portions. I was supposed to have ten gram portions of this and so on, so forth - two thirds of a slice of bread is a portion and so on, so forth. And off we were - we went home. And then, when I got home, I remember it was a Friday night and I was looking forward to tea, because we always had chips and egg on a Friday night, and it was my favourite dinner, with lots of bread and butter. And when I got home, Mom served out the dinner, and my sisters had theirs and they sat down and ate it, and I'm thinking "right, mine's coming now", really excited. And I had about three chips, an egg with no white and two thirds of a slice of bread and butter, and that was it. And I was mortified! And Mum was saying "well, that's all you can have", and I'm saying "but why? What did I do?". "'Cause you're not well, that's all you can have". And I just remember thinking "well, you know, what have I done? What have I done that I can't have the same?". And then sort of after that - jam tarts. That always came after chips and egg on a Friday, and I had an apple, and I couldn't understand why I was being treated so differently from my sisters. I'd just come out of hospital - I'm supposed to be the special one, you know, "why can't I have the same as everyone else?". And I think that's where the confusion started for me and the rebellious behaviour, because I just could not understand why I was being treated differently.

Was it that your mother wasn't really used to explaining things to children?

I think it's just the way it was then. Children were seen and not heard. They told my parents that's all they needed to know; my parents would do the rest. I didn't need to know why; I just had to do it.

(5) How did the different members of your family react to your having diabetes?

I don't really ever remember getting or ever discussing it with my sisters - I don't remember getting any feedback from them ever. My mother - I think my mother saw it as just something else she's got to deal with. Initially, I think she was concerned, but then after a while it became a chore - yet another chore on a very heavily burdened day. My father, who was more removed, because obviously we weren't living with him, was very matter of fact, you know: "you've got it, deal with it, get on with it" basically - still not knowing at this stage what it was. And then my mother got involved with the man who she's since married, and they had a very large circle of friends, and he had lots of relatives and so on, so forth, and they all used to come over to the house. And when they found I was diagnosed... The regular thing would be, there'd be like a little drinking party - you know, friends would come round and have nibbles and drinks and play some music, and the children would dance and entertain them, and so on and so forth. And once I was diagnosed, then people all started making kind of suggestions, you know, "she must have done something bad - God smite her", and things like that, not even realising, at this stage still, what they're talking about. I was

an evil child - I must have done something, Mum must have done something bad when she was carrying me, and now God's paying us back. There were all various suggestions about herbal teas that they would bring from Jamaica, bush teas that you could boil and you could drink, and I tried all of these - they were shoved down my neck.

So, was your stepfather from Jamaica then?

Yes, and a lot of his friends and a lot of Mom's friends were Jamaican and from the other West Indian islands. A lot of them - though not strictly Muslim - are very strict non-pork eaters, as a high proportion of the Jamaican population are, and a lot of the Caribbean islands. And their main concern, at the time, was to get me off this insulin, because it was pork, and I was committing a sin against God, which made me an even more evil person. I must have been evil in the first place to get the diabetes - still being evil because I'm putting pork into my body when God said we should not eat pork, and quoting Leviticus eleven, paragraph six, subsection five in the bible till I know it to this day. And various things - I was taken down Ladypool Road by other relatives, who again were Muslim, and found various vegetables,

- (6) one of which was so tough and like rubber, covered with bobbles, and bitter, but you had to eat it raw otherwise it didn't work. Unfortunately I couldn't get past two or three bites, because it was that tough, so I actually got a beating because I couldn't eat it and I obviously wanted to be diabetic, because I was an evil person. So, the main theme seemed to be, from a religious point of view, that I must have been evil. And also, if I had faith in Allah and in the Koran and in the teachings, then mind over matter. I believed God would take this away from me - that was very much the belief. And I must admit that over the time - I mean, this probably happened over a period of a few years - and I must admit that throughout the time, I actually became to believe a lot of that. In a way, in retrospect, it was actually... it's actually turned out to be a very good thing, because now I very much believe mind over matter in many, many cases, and in a lot of instances it's helped me overcome things that I may have otherwise run away from. But with regard to the diabetes, I was determined that yes, I believed in God, I loved God, I am a good person, so I'd stop taking the insulin for days, and I'd end up in hospital. And then they'd say "you didn't believe enough, you didn't believe strongly - you were only pretending. God knows". So, I'd believe even harder and I'd pray every day, and I'd stop taking the insulin, and I'd end up in hospital. And it just became an ongoing process, to the point where - at this stage I'd moved to the General Hospital in town at Steelhouse Lane, and the diabetic ward was ward one - and they actually had a room put aside for me, because every week I would be in there, because I'm trying to do without this insulin, because "my mind is strong enough, I can do this", not realising that it's not actually a mind thing. I still didn't know, at this stage, the extent of what was wrong with me, and why it was and how it

was caused and how to best deal with it. I just knew it was something bad, I must have been evil, and why the hell is it me? I kept saying “why me? What have I done? God, what did I do for you to punish me so badly?”.

What age were you when you moved from the Children’s Hospital to the General Hospital?

Between fourteen and sixteen; early teens.

And obviously, if you were almost coming once a week, the staff must have been concerned. Do you have any memories of doctors or nurses talking to you or to your parents?

I do. At first they were very sympathetic. There was a nurse who started called Sheila, and I actually was with her as she progressed through to Matron every week. And we became pretty good friends and we talked, but then, after a while, the sympathy went and turned to irritation - “why can’t this person just do what they’ve got to do?”. And instead of going “oh, hello, how are you this week?”, it was “what - you again?”. The doctor, Dr Natrass, had told me that if I continued the way I was going, I wasn’t going to live to see fifteen, and I was determined that I was, and I did, and I told him!

(7) And how did your mother cope with your behaviour?

It was quite difficult for her, I think. Yeah, looking back, it was very difficult for her, but it was also very difficult for me. I don’t think she ever understood - even to the day she died, I don’t think she ever understood where my behaviour came from. And it wasn’t until much later on in my life, looking back and actually analysing it, that I actually realised that my behaviour stemmed from ignorance. I didn’t know what was happening to me, I was never told, so my automatic response was to rebel, so everything she did for me, I rebelled against. And by the time I was about eight or nine, perhaps ten, she couldn’t cope any more, and she got in touch with social services and so on, so forth. I was disrupting the family, I wouldn’t take the insulin, I was being hospitalised weekly, I would steal bottles of Alpine fizzy pop, knowing I’m not supposed to drink it. She had to go to the shops en route to school and tell them not to give me sweets and so on and so forth. And she couldn’t cope, so in the end she sent me to boarding school.

How long were you there?

I was actually there for about eighteen months. I was taken out because I was becoming educationally subnormal. My father was very much on education. Although we only saw him of a weekend, he made sure every weekend we did some maths, we did some English, we did some Spanish and French, because, obviously, he’s French and Spanish speaking. And within eighteen months, I’d done all of the work that they had available in the school, and we hadn’t realised at the time I actually went there that the level, educationally, was as low as it was. So, my father insisted that I be taken out of the school and I went back into mainstream school. I went into the first year at the Maypole Comprehensive

at 1-D-1, which is the bottom class, and by the end of the first year I was put into 1-A-2, and I stayed there throughout the rest of the school year... well, the school time.

And did you have the normal teenage rebellions over sort of drink, drugs, sex, etcetera?

No, I didn't, actually. Drink's never interested me - I've never had an interest in drink, even now as an adult. Occasionally I'll have a glass of wine, but apart from that, no. I used to smoke. I used to smoke cigarettes from I was about fourteen, fifteen, but there again, I think that was just another form of rebellion, and I think it was me having control over something!

- (8) At least I can control whether I smoke or not - you can't take that away from me. No, my teenage years - I actually left home when I was fifteen. The relationship with my mother had become that strained that we just couldn't live together. I never stopped loving her - never ever stopped loving her - but we just could not live together. And that continued, even into adulthood - we couldn't live together. We were just too... I think we were too alike in a lot of ways. And it was difficult for her, and I think she also had perhaps a lot of resentment - if that's not too strong a word - against the way I'd behaved, because my other two sisters were 'normal'. Even my other sister, you know, after her illness was 'normal'. And I was - and still am - the black sheep of the family, and it's just a role that I got used to and thought "okay, if this is how you see me, this is how I'll be". And I've always been very independent, very headstrong and very determined.

Where did you go when you left home?

Various places. First of all I went to stay with a friend in like a kind of squat, kind of thing, which was difficult. Managing diabetes with no food, no drink, no money - very difficult, but I managed. My body, I think, by then had become accustomed to doing without insulin for a while, which was not good, but then I'd sort of go home, grab a shot, go again, get some food and so on, so forth. And it continued for a while. I was gone from about... a good eight or nine months, and then I used to live down at Sparkbrook, Small Heath, with a friend. She'd got a flat down there, and I was there for perhaps another couple of months. Mom didn't talk to me, didn't want to know. I was quite happy just doing my thing, but I wasn't actually doing anything, if you're with me. In fact, it wasn't fifteen, it was sixteen - I'm lying - because I'd actually finished school. And that was one thing that they couldn't take away from me, because when I was at school, as well, it was another rebellion thing. I didn't go to school for the last two years, because of the 'diabetes'. It was nothing to do with the diabetes - I was wagging it, but that was the excuse I always gave and they didn't dare to question that. So, when it came to doing the exams, now they refused to let me sit the exams, because I hadn't done any of the coursework. But my parents argued, because every night I'd be home studying. Every single night I'd be

home, and what would happen is, I'd go to sit in the flats with my friend or go to a friend's house and smoke and have a laugh and chats and so on, and then meet people on the way home from school, take their work and go home and learn it. So, my parents argued that I'd worked, I'm ready, I need to take these exams. The school said it would be a waste of money and they weren't prepared to do it, so my parents said "okay, we will pay for any exams that she fails". So, on that understanding, they let me sit CSEs. I originally had been up for GCSEs. And I came out with six grade A's, and they sent the results back to be checked. The only one I failed was English, because I hadn't done the coursework. And that just gave me even more determination, you know, I thought "well, two years I haven't been to school, I've walked out with six grade A's - don't tell me I can't do anything", you know, because that was a running theme throughout my childhood. I remember that strongly from every avenue, except my father, who was non-committal either way, but my mother - when I wanted to learn to drive - "you can't do that, you're too thick". When I said I wanted to go to university - "you'll never get to university. Nobody in our family's been in university", and to date, apart from me, nobody still has.

(9) So, what was your life like, then, after you got these six grade A CSEs?

Not that different, to be honest; not that much different. As I say, I left home, wasn't really doing a great deal of anything, but got involved with a lot of nice people who showed me alternative ways to make money, and so on, so forth. But I think, because of the rigidity and discipline of my upbringing, I never got tempted. I never got into robbery and burglary and nothing that's illegal. I've always had in my mind that that's not for me - I'm better than that. But I did get involved with the Rastafarian... a couple of Rastafarian people, and got involved in the reasonings - what they call the reasoning sessions, which is where you talk... obviously the doctrines of Rastafari and with references to the bible and today's life, and so on, so forth. And when I went to my first reasoning and actually met the group, they seemed to accept me quite readily, until they found out I was diabetic. And when I asked them why, they said it's because of the pork. And my argument was "well, it's a greater sin against God to commit suicide, and if I don't take this insulin, I'm going to die". And they were saying - once again, like my parents' friends - "but if you believe in God, God will prevail, God will take this away", and I said "but what you don't seem to realise is is God give me this in the first place!", you know. And I said, you know, "at the same time, though it's pork, it's still a way in which I can maintain my life, and I really don't have an option, because the other alternative is too painful and certain death". And they really, really struggled with it, to the extent that I didn't go back. I did defend Rastafari for many, many years, and still do in my heart, even though I don't have dreadlocks any longer. But for many years thereafter, people that had actually been in that reasoning with me used to call me a - what was it - a wannabe dread, a false dread, because I was taking pork. I was breaking one of the fundamental rules of Rastafari, which is not to eat any pork. I've never eaten pork, I still don't eat it, but it's ironic that I had to depend on a pork substance to keep me alive over all those years.



(10) What did you do after you left the Rastafarians?

I never really left the Rastafarians - I still have Rasta in my heart. It's a very difficult doctrine to understand, but I never left. However, after that experience, I never mentioned the diabetes again - I tried to pretend it wasn't there. I left home, I went down to London, had some homeless episodes. Spent a few nights sleeping in doorways under cardboard and so on, so forth, totally trying to ignore the diabetes, thinking "if I pretend it's not there, it won't be, and I can just carry on and get through this". I rationed my insulin. I had it with me, but I rationed it, and would perhaps take a shot every couple of days, eating as and when, if at all. And it very soon became, you know, sort of a routine, a way of life. It was only over a couple of weeks, but I amazed myself how I was able to adapt. And I've since heard people talking about things you can and can't do with diabetes - trust me, it's rubbish. There's nothing you cannot do if you want to do it badly enough. That's one thing that has kept me going through everything in my life. I truly believe that if I want something bad enough, there is nothing that would stop me doing it.

When you were leading such an irregular homeless lifestyle, did you have lots of hypos?

No, because I was more often up in the twenty fives, thirty fives, than I was down in the lows, because I wasn't eating, which meant I was producing ketones. I know that now. Yeah, I was producing ketones. I wasn't doing anything to burn off the excess sugar, I wasn't taking the insulin regularly enough, so my body, by this time, had become accustomed to coping at such a high sugar level. Not that it was good for my body, but it had just become used to coping with it. And I don't know what it was, but the prevailing thought was "I'm not going to die - this is not going to get the better of me". And I still feel like that today - this is not going to get the better of me. I will lead a full healthy life, and have done. It's been difficult. My time in London was hard, and culminated in me actually coming back to Birmingham

(11) to be hospitalised, quite poorly. I had kidney failure and so on, so forth.

How old were you then?

I was about eighteen at this time - in fact, I was eighteen; I remember I was in hospital on my eighteenth birthday. And this is really where the changing... the turning point came for me. I met a girl who I'd been diagnosed with at the same time in the children's hospital, only, at the time, I didn't realise we had the same diagnosis, because I didn't know what the diagnosis was. So, we were both approaching our eighteenth birthday, but her bones were crumbling, her spine had started crumbling. She'd lost her sight, she'd lost kidney... she had massively reduced kidney function, she had major nerve damage and had to have half her foot amputated. And it frightened the life out of me - it frightened the living daylights out of me. And I set out, then, to actually find out what the hell is going on - what is wrong with me. And it was strange, because once I'd made that decision, I then approached the nursing staff and the medical staff, who

laughed at me, because by this time I'd been diabetic for eleven, twelve years, and I'm supposed to know this. And they laughed and told me I was being stupid - don't ask them such stupid questions. So, I didn't, but I got books - I went to the library. I picked up any literature and every piece of literature I could find and actually read about it, and taught myself what was happening, and actually found a regime that works for me. When I was eighteen, I was told the regime that I was using was bad and I should do it their way and not my way, and, as a result, I didn't actually go to the hospital for about fifteen years. And the understanding was: when I needed them, I'd go. And when I went back after that time, went to see the nurses for a review, I was amazed to find that the regime I'd been following was the regime they were now telling people to use.

So describe it then.

I took the insulin as and when I felt I needed it. Really, I was guided by my body, and still am to this day. These days it's a bit easier, because obviously you can check blood sugars, but back in those days I was guided very much by my body. If I wanted to eat, I would eat, I would take insulin. I used to take ActRapid and Ultralente, and I actually worked out that if I take the ActRapid after I've eaten, I feel better, and then take the Ultralente in the evening. And that's the regime that they actually use today. And I turned to Mark... I remember turning to Mark and me saying "well, look at that. You told me all those years ago I was wrong, and I was going to be dead - and I'm still here", you know!

- (12) So, now we've got you on a regime, that you really devised yourself, from the age of eighteen for the next fifteen years. Can you say what happened to you in those fifteen years?

Once I'd decided that this thing was not going to beat me, that I was going to take it in hand, I was able to sort of look forward. I was with a partner I'd been with for a while, on and off, and got pregnant with my first child when I was twenty one, twenty two. I was advised by the hospital not to have the baby. Because of the uncontrolled level of my diabetes, and the way it had been out of control for a while, they reckoned that my child would be born without fingertips, possibly blind or deaf, and most certainly with some sort of respiratory problem. And I decided that that wasn't going to happen. Really tightened up on the diabetes - really tightened up on it - and almost did it sort of to the book, at that stage. But I found that by doing that, I put on an awful lot of weight; an awful lot of weight. I had a very... the first half of the pregnancy was really nice - there was no difficulties whatsoever. There was no morning sickness, blood sugars were fine, health-wise I felt really good. But then the second sort of... not the second set - the third trimester, I blew up. My legs blew up, my feet blew up, and I was taken into hospital for the last, it was about ten weeks, and then six weeks early my son was born. I went twenty one hours in labour, until they realised that his head was too big to actually come through my pelvis, and then had emergency caesarean. And then, yeah, had a lovely boy - nine pounds two. They reckon, had he stayed for the next four weeks, he'd have doubled in size, so I'm really grateful he came when he did... well, they actually started

me off early - they started me off because I was so big. And then, yeah, settled down as a single parent, had major postnatal depression.

Which year was he born?

He was born in 1985, and very shortly... well, just before he was born, his father and I had had a stupid argument over what his name would be, and his father actually decided to hit me. Well, I actually saw my parents involved in domestic violence, and had made

- (13) the decision that nobody was going to hit me, so once he did that, I walked out. And that was it, I would not go back. So, I found myself at twenty three, a single parent, living alone with postnatal depression and diabetes and a new baby! So, it was a lot to deal with. The diabetes, really, even today, I try to keep in the background. My main focus was looking after my child, keeping my place clean and making sure he's fed and so on and so forth. The diabetes was just by the by. It had to fit in as and where it could. And I was constantly minded and reminded by doctors and medical practitioners of the dangers and the damage I was doing to my body, and so on and so forth. But at the stage I actually realised the damage that I could have - and probably have - done was too late. Had I been told when I was a young child and newly diagnosed what was actually happening to me, what the process of events was going to be, how I could best deal with it and avoid these things, then I think it perhaps would have been better. But to have been told "if you don't do this, this is going to happen" is very difficult, for a child especially, to grasp that concept. You need to see a train of events in order to appreciate the consequence of an action. There was a lot of confusion - an awful lot of confusion. And I had my son and we were alone for eight years. My mother died when he was five years old in 1990. I actually gave up work to nurse her through the last stages of cancer, which was very difficult. I made a decision, with her, that my son wouldn't see her, because she didn't want him to see her in her last, you know, stages before she died. She wanted him to remember her how she was. And because of that, we didn't let him see her before she died, and it actually gave him major, major psychological difficulties. And by the time he was eleven, twelve, I had to get him into counselling - private counselling that I had to pay for, which was very difficult. But because he had to have counselling, I had
- (14) to get involved as well. And it took me a long time to open up and actually speak about my younger years, because I'd actually closed a lot of them off, and it's only after working on a personal life history I've been able to remember so much. But we actually discovered throughout my counselling session that a lot of my behaviour, and feelings that I'd carried to that date, actually stemmed from the fact that I'd been kept in ignorance - that I'd been diagnosed with what was a critical illness and just told to follow the rules. I'm not told what it is, how it's going to affect me, why I've got it - "just get on with it. Don't ask questions - just do it". And

at that stage I was twenty... about twenty six, twenty seven... no, I was older than that... sorry, I mean up until 1996. Sort of a couple of years prior to that, in 1992, I had my second child; a little girl. That was also a very difficult pregnancy, and I had a lot of trouble with hypos with that pregnancy. From before the pregnancy was actually confirmed I started having hypos, and had hypos thereafter every day for the rest of the pregnancy. Got to the stage where the GP was coming in every morning to administer the Glucagon, and taught my partner how to do it, and so on and so forth. I couldn't eat, I couldn't drink, I vomited every day. And after I'd had her, I actually weighed less than I did before I was pregnant, because she'd just taken so much out of me. And it was a really traumatic experience, actually. She was also delivered by caesarean, but emergency caesarean, because she decided to come early - on her own at home, with the cord wrapped round her neck, so I had emergency caesarean for that as well. But I found... with both my pregnancies, actually, it was quite strange and quite funny, because when I was admitted, the nursing staff initially wanted to be all into the diabetes and tell me to do this and tell me to do that, and blah, blah, blah, whereas at this stage, I'd probably had it for almost twenty years. And it was actually Dr Wright who was looking after me whilst I was pregnant, and I spoke to him on the phone one night, because the nurses were telling me to take insulin that I just didn't need and I wasn't prepared to take. So, I phoned him and told him my reasonings, and he said "well, okay I agree with you". And he turned to the nurses and he said "look, leave her alone. Let her do what she needs to do". And thereafter, the nursing staff didn't bother. They provided me with the insulin, they made sure I took it, but they'd say to me "right, how much are you going to take now, and why?". And I'd say "well, I'm not very hungry - I'm only going to have a sandwich. I'll just have six units". "Okay, that's fine".

- (15) You mention that you had a partner by the time your daughter was born in 1992, but before that, when you were a single parent, did you feel vulnerable that you might pass out?

Yes, I did, very much so, and my way of coping with that was always to make sure I was running slightly high. I'd always feel better running slightly high than on the lower side, because I was always conscious that if I went into a hypo, and therefore lost consciousness, I would have a six month old baby with nobody to look after him. So, that was very much in the forefront of my mind. And I suppose, in retrospect, running it as high as I did didn't help, but it was a coping strategy that I needed at that time.

And how did the men in your life cope with your diabetes?

Different people, different ways. But the main theme has been either they ignore it and pretend it's not there, or in some cases men have actually left once they've seen me take an injection, because I must be a freak - there must be something weird and wrong with me. My partner now, who I've been with for over ten

years: cannot fault him. Over the years, he's become to know as much as I do, almost, about the diabetes. He regularly helps me out with hypos. When I had hand and shoulder surgery recently, he did my blood tests, he did my injections, he prepared my food. Cannot fault him - one in a million, but a very, very rare attitude, I must say, amongst the people that I've met. Women seem to take it on board easier - seem to be more accepting and take it more in their stride. Men seem to have a real problem with it. But for me, that's almost been like an indicator of whether I want to be involved with this person or not. "If you haven't got the maturity enough and the common sense to realise that I have no control over this, that this is just as it is. It doesn't make me any less a person than anybody else, it doesn't make me any more weird or, you know, incapable than anybody else. It's just a fact of life: I have to take a couple of injections a day to live a normal life. If I don't tell you, you don't know about it. So, why all of a sudden, now you know of it, it's a major problem?"

Did you do any paid work while your children were growing up?

Yes I did - I've always worked. From the age of sixteen, I've worked. Initially I wanted to be an air hostess, but was told, because of the diabetes, I couldn't fly, so I was gutted. Then I wanted to be an interpreter, because I'm very good at languages. I enjoy languages and I actually speak five languages quite fluently, but again, there was a great deal of travelling involved in that. So, I was dissuaded against that, primarily because I wouldn't be able to get insurance - airways, airlines wouldn't insure me for regular frequent flying without a medical person on board. I think it was ludicrous, it really was. And I sort of tried an assortment of jobs throughout the time. I mean, eventually I went to university, did a law degree, and so on and so forth, and qualified as a solicitor. But prior to that, I worked in the insurance industry. And I was actually headhunted for one of my jobs by a manager, and went to work for him, did very, very good, became his office manager, and then he moved firms. And when he wanted to take me with him - he moved on to another big firm called Schroder, who were one of the biggest, at the time, in financial management - and they refused to take me, because of the diabetes. The position came with life policies and pension and certain medical benefits, and so on and so forth, and because of the diabetes, they just wouldn't employ me; they refused point blank. He tried his utmost to persuade them of my work record, my dedication, my expertise, qualifications and so on, so forth, and they said that diabetes precluded me from being a member of their staff.

(16) What year was that, that you were turned down?

It would have been 1991 - it was the year after my mother died. And then, that was my last experience with insurance. I left the industry, then, totally. I'd always had an interest in law, and I had done an A Level and an O Level at this... an O Level and A Level at this stage, and went on to do the Institute of Legal Executives course at Solihull Technical College. I did that for four years and passed all of those exams, and the tutor suggested it might be easier if I went and did a law degree, because the ILEX route was actually so long

and drawn out. So, I went to... I had started university earlier to do law at Birmingham, in the late eighties, but because of difficulties with my hands, due to carpal tunnel and so on, so forth, I had to stop, because I wasn't able to write. So, the second time I went back, I went to UCE in Great Barr, and did an LLB with honours there and completed in about '97, '98.

And you've mentioned carpal tunnel problems in your hands. What other complications have you had?

I've just actually had the fifth operation for carpal tunnel on my hands. I've had the carpal tunnels done - both hands twice, one hand three times - I've had the flexor tendons done on each hand, I've had a shoulder cuff decompression done. Other difficulties: I've got periphery neuropathy through hands and feet, papillary necrosis. I've just been diagnosed with... I can't remember what it's called, but it's a diabetic... it's a problem, a nerve... it's a diabetic complication that affects the nerves in the stomach, and affects my ability to digest certain foods, which means that I can't eat any fruit or vegetables, any salads, anything green, no dairy products, nothing like that. Oh gosh, there's just loads of bits and bobs that I can't sort of mention all at once.

Do you connect those with your earlier irregular lifestyle?

The neuropathy, definitely. I mean, I think I'm very fortunate that, after thirty six years, I've only got a sort of - you know, and it's not even that severe - a degree of neuropathy. My eyes are fine. I've got kidney damage, but it's not extensive. And in every other respect, I'm totally normal. I mean, I do have sort of days when I feel totally unwell and unable to function, and it tends to be down to the diabetes, but other than the diabetes, I'm in pretty good health, and always have been.

And how have you made a living since you got your law degree in '97?

I've actually practised law... I've been practising law, on the whole, for sort of twenty years, in different capacities, as secretary, and legal assistants, and so on, so forth, and worked my way up through it. I practised with two firms in Birmingham city centre for quite a few years as a fee earner, doing personal injury and civil litigation. I was also an office manager for two of those. And following that, I was the manager of a barristers' chamber in Birmingham, looking after twenty six barristers - single-handedly, I might add - which was quite difficult, and very stressful. I do a lot of community work. I also do counselling, and so on, so forth, and I've done work with women and children in an advisory capacity, and also availing functions and services to them.

(17) And can you talk about some of the changes in the treatment of your diabetes over the years?

Well, my time frame might be a bit scatty, so bear with me! When I was initially diagnosed at the hospital - in the children's hospital - I was given insulin that I then had up until I was about fifteen, sixteen. And at that stage, my diabetes was so out of control that they said they had serious fears as to my mortality.

And what they could offer me was a new product that had come out called the NovoPen, but we would actually have to pay for it. And I remember actually asking my Dad for the money to do this - it was sixty pounds - fifty, sixty pounds - and he refused. And I just remember being gutted, and it was actually my stepfather who stepped in and fronted the money for it, so we purchased a NovoPen. The NovoPens had to be purchased, but the cartridges and the pen-tips - the needles - came on prescription, which was really bizarre; really, really bizarre. And I started having two or three injections a day, at that time, and then one throughout the evening. And then, since that, I've tried a couple of different insulins. The reasons I've had to change the last two times is because I was having hypos but no symptoms, and they thought that change of insulin might actually help that. Initially, it seemed to. I went onto Humalog and Humulin, which was apparently brand new insulins with the NovoPen 3. And they were very good, but I was still having hypos and going down as low as one-point-eight with no symptoms, which was very dangerous. Obviously I drive, I take my children out, and I can't be functioning on a one-point-eight with no warning. So, I went back to the hospital again, and they actually put me... I'm still having the Humulin, I believe - I always get those two confused - I'm still having the Humulin, but I now have one called Levemir, which apparently is a brand spanking new product. And it's absolutely superb. It feels as if I have a totally new lease of life. It's given me much more freedom - I'm much less rigid now in the routine - it gives me that more flexibility. And I think I'm now - at the age of almost forty three - finally understanding what's happened, what I've been living with all these years. And it saddens me that I've had to go through so

- (18) much to get to this stage, when it all could have been avoided, and perhaps my life could have been so much different, had somebody just had the decency to explain to me at the time of diagnosis what exactly was happening. It would have saved so much trouble and heartache. It seems like such a simple thing - you know, "we'll leave it to the parents to tell the child" - but the repercussions from that and ramifications of that just could not have been anticipated. And though it's been hard, I'm at a stage now where - in fact, I was talking to my partner about this the other day, where I said "I'm really grateful for the diabetes", and he said "that's really strange". And I said "I'm grateful. I thank God every day for the diabetes", and he said "well, why?". And I said "because unless I tell anybody, nobody knows I'm diabetic, and it could be a hell of a lot worse. I could be blind, I could lose the ability to speak, I might be paralysed from the neck down. I thank God every day for the diabetes. If I have to have a critical illness, give me this, because nobody knows unless I tell them".

Have there been any positive advantages from your experience of having diabetes?

Positive: I think perhaps in the way that I think, and my personal outlook, definitely. Otherwise no, I can't see any stage in my life where it's helped me

advance in anyway, no. If anything, it's probably been a hindrance in a lot of ways.

How would your life have been different if you hadn't had diabetes?

I've thought about that often, but it really is difficult to say. I'm forty three, and for thirty six years of those I've been diabetic, so I really cannot imagine living without it. We saw an article on the television the other day where they were saying they can actually implant new cells that can regenerate the pancreas and rid people of diabetes, and so on, so forth. And my partner asked me would I like that, and to be honest, I really don't know. I think taking the injections, doing the blood sugars and being constantly aware of my food intake has become such an integral part of my life, it would be like cutting off a limb to not have to take the injections any more. Does that make sense? So, I don't know if I would take that option.

What would your advice be to someone newly diagnosed with diabetes?

Find out as much as you possibly can. It can only stop your life if you choose to let it -

- (19) it can only change your life if you choose to let it. You may need to change your way of eating, your time of eating, you may need to be more mindful of your blood sugars, and take a little bit of time in the day for yourself. But at the end of the day, if that's all it takes to have a healthy life, a normal life, then do it - absolutely do it. You know, the only person that can stop your life progressing in the way you want it to is you. You can try and blame the diabetes, but at the end of the day, you control that as well. Another thing I would say is, it's really important to avoid stressful situations or the build-up of stress. It is difficult to do, but you need to sometimes take a step back and sort of have a look and see what's going on. Stress has affected my diabetes really quite badly over the years. It has exacerbated my stomach problem, it caused me to lose my voice for a five, six month period. I was working sort of three years without a break, constantly, and though the diabetes was there nagging in the background, I kept pushing it back - just dealing with it and pushing it back and pushing it back. But I think you need to be mindful - you need to listen to yourself. It's so easy to say "I'm fine - I'm okay. Everything's fine", when, in the back of your mind, you really know "I'm really struggling here, I'm really struggling". And I think that's the important thing. You have to look at yourself, admit that to yourself, and just take a step back, because it really can make a major difference. When I'm stressed, or when I'm feeling unwell or whatever, it shoves the blood sugars up, but stress is the worst one. If I have an argument with my partner, a really big - I mean, we've not had one for years - but a really big blow-out, screaming and shouting and everything, you can guarantee that within a couple of hours my blood sugar's through the roof. Don't know how it works, not sure how it works, but it happens every time. Blood sugars go up, body starts feeling sluggish



and really slow, you start feeling really lethargic and you've got no energy, can't be bothered. And people think "oh, I'm just tired", but it isn't - it's the stress and the diabetes reacting quite badly to each other.

How much contact do you have with the medical profession nowadays?

I tend to see my GP quite frequently. I go to all his diabetic clinics, so he monitors me and keeps a check on my weight and cholesterol and so on, so forth. The hospital: I tend to go as and when I need them. That seems to be an understanding between us. They don't get upset if I don't go - in fact, they don't send me appointments any more. I phone them and say "look, I'd like to see somebody", and then they send me an appointment. I think for me, at sort of thirty six years, going to the hospital is a moot point - it doesn't make a great deal of sense. There isn't anything they can tell me. And that's not meant to sound bigheaded, but unfortunately, the last time I went to the hospital at Selly Oak, I actually saw a consultant who was younger than the amount of years I've had diabetes. Now, how does that work? What could they possibly tell me, you know? And I tend

- (20) to get a little irritated, sometimes, when you go in and people say "right, now tell me about yourself". You can't just recall and retell thirty six years of history in five minutes, you really can't. And I struggle with the fact that somebody's got three folders in front of them and are asking me to sum it up in two minutes what's going on. You know, if you're taking the trouble to see me as a patient, at least have the decency to read my notes to find out where I'm at, you know. So no, I don't tend to go to the hospital that often for diabetic checks. I do go regularly for my eyes, I go to a chiropodist every six months, and yeah, I see my GP quite regularly.

Have you had much contact with specialist diabetic nurses?

I remember three episodes, the first of which wasn't very encouraging. I found they were quite patronising, I found that they didn't take me seriously. Again, it was that old attitude "well, if you've had it for so long, you should know everything there is to know", and I'm thinking "well, obviously I don't or I wouldn't be asking questions". But I've found the first experience that I had was very negative and didn't make me want to go back again. The second experience I had with the nurses, when I went for a change of insulin, was that brief it doesn't really count as a visit. But the last time I went, which was when I saw the lady who gave me the number, she was very good. She sort of brought me up to date on what had happened, told me about the new insulin, checked on my regime and my blood sugars, all my equipment, to make sure everything was right. She was very, very helpful, and I got quite a good vibe from her. I did sort of open by saying to her "look, I know I've had it forever, but there are still things I'm unsure of. Can you help me out?", and she was brilliant; she was really, really good. So, yeah, top marks for the last visit I had.

- (21) And what changes have you noticed in society and society's attitudes to diabetes?

It's much more widely known these days. When I was first diagnosed, it was very rare, especially amongst children, and the attitude was - it was something, but nothing. You could get rid of it if you really wanted to - you know, just a little bit of sugar, nothing big. But sort of nowadays, with more people being diabetic and being aware of diabetes, I'd like to say it's a little bit more important, but I don't think that's the right word. It's more renowned, but I think people's attitude towards it is "I've got a little sugar, I've got the sugar". That's a lot of the attitude - "I've got the sugar" - like it's nothing. I think it's become so popular, now, that society's played it down to be much less critical than it is. It can be a very debilitating illness. The consequences of bad control and so on, so forth are, and can be, quite severe, but these things are not pushed. The attitude of newly diagnosed diabetics, as I know it, is that they're in hospital for a day, they're told what diabetes is, they're shown how to do an injection, and they're sent out, and that's it. Diabetes is far too complex to be learnt about in a day, especially if you're going to have to change your whole life to actually coincide with that. Medically, doctors and so on, so forth are a bit more aware, and a bit more... well, if you were to have a stomach problem and go to the doctor's, he will sort of look at certain... stomach problem, for example, he'd look at certain tests and blood tests and so on, so forth. But with me, if I have a difficulty - "oh, it's the diabetes". He won't even investigate it any further, in some cases, till I have to put down and say "look, I'm not only a diabetic, I am a person, and there are other things happening with me". And I think that was very much the attitude. If you're diabetic, you're categorised as "yeah, they're going to have a problem, just put them over here". And everything's down to the diabetes. You couldn't possibly have, I don't know, a stigma in your eye, for example, because you're not diabet... if you've got a diabetic, it's because of the sugar, you know, and everything's blamed on high blood sugar and so on, so forth. It used to be a lot easier to cheat

- (22) in the earlier days; much easier. In the days when they were urine tests, which were totally unrepresentative, because if you hadn't had a wee since the night before and you got up in the morning, your urine test was reflecting what your blood sugar was before you went to sleep. Took a long time for people to catch onto that, I reckon. However, there was a way round that. We had to wash out... we had a little test-tube and a pipette, and you had to put five drops of urine and ten drops of water with a little Clini... oh, god, what's the name... with the Clinitest tablets. If it turned blue, it was good; if it turned orange, it was bad. And after a few oranges, I thought "I don't like this. They keep scowling at me when it's orange", so, in future, what I used to do was just wash out the test-tube, fill the pipette with water, pretend to draw up the urine, and just put five drops of water and ten drops of water, put the little tablet in and go blue every time! And it'd be excellent - I'd get really good results. But nowadays they've got fructosamine tests, so if you take a shot half an hour before you go to the doctor's, your blood sugar may well be four-point-five, but your fructosamine is showing them that you've been running at an

average of eleven-point-six for the last three months! So, it's not so easy, now, to cheat as it was in the earlier days. And they're much more precise now. Blood tests make life a lot easier. People sort of say "well, ooh, how can you, you know, prick your finger five times a day?". I sometimes do it up to ten times a day. It gives me peace of mind, it helps me keep on top of it, and at the end of the day, it's a very little sacrifice for control. I like the idea of the more regular insulin as well. If you're not hungry, you don't eat, you don't take insulin, whereas in the early days, from I had an insulin shot in the morning, I had to eat at eight o'clock, at one o'clock and at six o'clock. If I didn't, there'd be hypos and there'd be all sorts of sweaty flushes and so on, so forth. But with the regimes that they have today and the flexibility, I think it's much easier to be a diabetic in this day and age than it was when I was diagnosed, but I think they could do with being better informed.

(23) And how have your attitudes to food changed over the years?

Very drastically. I used to really enjoy food, but since it had been limited and restricted, it became less enjoyable. I had a bout of bulimia in the late eighties, early nineties, perhaps, I reckon, as a produce of stress relating to postnatal depression after the pregnancy and so on, so forth, my mother passing away at the same time, a very close sort of - I haven't mentioned it before - but a sort of surrogate mother from London also dying the year before my mother did, and yeah, I had a child as well. And had bulimia for about six years, which was very, very difficult. I started to try getting back into some regular routine of eating, specifically focussing on fruit and salads and vegetables and stuff, which I really enjoy, but found after a while that I started bloating and getting a lot of pain and discomfort. And after various trips to the doctor, and so on, so forth, we had a locum doctor come in who suggested that perhaps I try limiting the amount of green stuff that I actually eat. So, by process of elimination, I cut out everything, and then tried introducing one thing at a time as it goes on. The consequence of that is that I'm now unable to eat anything green - fruit, salad or vegetable, no dairy products, no eggs, and it's very difficult, because I love salad and fruit and so on, so forth. However, I do maintain a healthy diet for my family. Being the mother who's diabetic, I'm aware that my children are more prone to diabetes than perhaps children who don't have diabetic parents. Furthermore, my daughter has a higher risk, because her grandparents and her grandparents' parents also have diabetes on the female side of the family, so I think she's even more prone. And I think it's important for people with diabetes to be mindful of their families and be aware that if you have small children and you are diabetic, or diabetes is in your family, then the best thing that you can do for your children is to actually give them a healthy diet. Make sure they have a reduced sugar and salt diet with reduced fat. Get used to, from a very early age, eating healthily, then they won't be sort of as tempted by the sweet stuff and the fizzy drinks. We have no fizzy drinks in our house - all our drinks are sugar free or fruit juice or flavoured water. We only have fresh fruit. I allow one bowl of sweets in the house per month, and if you finish it in the week, that's

fine, 'cause there's no more for the rest of the month. But there tends to be, at the end of the month, sweets and stuff left over. And it's really nice for me, if I take the children out and give them an option at McDonalds, and they actually ask for a salad! That is really, really good, you know - it's a bit of a boost. But that's the best thing you can do for your family as a diabetic parent.