

(1) Tell me about your background.

I'm the seventh daughter - well, I'm the seventh child of ten, 'cause I've got a half-sister in Jamaica as well. But my Mum and Dad have got nine children together, and I'm the only one that's known to have any illnesses out of the whole nine of them, or the ten of them, yeah.

What about your aunts and uncles and grandparents - any talk of illness with them?

No, they're all all right, actually. I mean, on my Mum's side, my aunts and uncles - they suffer with cancer, but on my Dad's side, I think they say that my one auntie's got renal disease, but she's got that due to having a child or something; it wasn't inherited. And there's no signs of anything else, no.

When did your parents come here from Jamaica?

Oh, in the fifties - mid fifties, they came on their own. They had my elder sister, elder brother... my two elder brothers and my elder sister, they were left in Jamaica. And they came over here and they started their new family, which was my elder sister, my two elder brothers and me, and then there's a gap of six years, and then there's my younger brother and my younger sister.

And what work did your parents do?

My Dad's a builder - he's now known as a master builder, and my Mum, she did auxiliary nursing, but having all these children, she never had time to hold down a permanent job of nursing, so, yeah, she did nursing.

Do you know how they found England when they first came here?

Very cold - Mum always said it was very cold, and it wasn't... But my Mum and Dad, they came across to the English way. They didn't come across like "oh, this is another Jamaica". They came - "this is England, do as the English do", you know "when in Rome, do as the Romans do". So, they're very westernised, they're very English - live a very English lifestyle.

What do you mean exactly?

Well, you've got West Indians that live a very West Indian lifestyle, but my Mum and Dad, they live a very English lifestyle. You know, they don't live in... they didn't live in like areas of great black people, like they didn't live in... they moved away, so there was very few... I mean they've got friends in the black community, but they didn't live in a heavy set black community. I don't know whether they preferred it that way, or that's just the way that they found how they could move on.

Where were you brought up?

I was born and bred in Bearwood, which is a very heavily English populated area, thirty seven years ago, so, yeah. And we've always lived within this area -

Bearwood, Quinton - but now my Dad lives in Solihull and my Mum still lives in Quinton, yeah.

How did you find it at primary school with

(2) mainly white pupils?

It was all right, because we were brought up that way. If you were brought up in a black community and you met black kids then you'd get used to that, but it was like you had to make friends with people that didn't like you, and it was very, very, very difficult. So, as you were growing up, a lot of black people would think that you didn't think that you were black because you could accustom yourself with white people more as that they could, because they were growing up with black people. But it didn't mean that I thought I was white or acted white; it was just the way that I was brought up. So, I mean, we understood the black side of it and we understood the white side of it, which I thought it was a benefit, but a lot of black people didn't agree with that.

But you say you had to make friends with people who didn't like you. What was that like at primary school?

It wasn't so much primary school, it was senior school. They'd rather spit on you and you know, there was a lot of skinheads and racism around then. And then we moved from Bearwood to Quinton, where there was a great amount of them. It was horrible, but you just learned to live with it. I think we had it worse than black children that lived in black communities because we had no... we didn't have a big amount of black friends to live with to do that. But you learnt to live with it and you just get on, and now the people round here know me, 'cause - "oh, known Patsy years, she's always lived round here", so, you know, "we went to school with her" and whatever, so, yeah.

Now, tell me about your diagnosis with diabetes. How did that come about?

I was in the fourth year junior school, and I didn't notice it, but Mum noticed that I was drinking more fluid than anybody else going - I could drink the tap dry, and I was forever going to the toilet. And we went to... it was a road trip to Weston-Super-Mare, and they had to stop the coach three times for me to use the toilet, and my Dad's going "this is getting embarrassing", you know, "what is wrong with her?", and they didn't realise. And then they took me to the doctor's and they did blood tests, and then I was admitted into hospital and they found out that I'd got diabetes.

Which hospital was it?

That was City Hospital; it used to be called Dudley Road, all those years ago.

How long were you in there?

Weeks. It seemed forever, especially when you're eleven, going on eleven, twelve, and you want to be with your friends and your family, and you've been restricted

from all these things and stuck in a hospital; it's not very nice. It just seemed like... oh, it seemed awful.

Can you remember what you were taught about diabetes in hospital?

I remember them teaching me how to give injections, and looking for the warning signs for hypos, and your diet - oh gosh, your diet was the big thing, because it's not a diet like what you've got these days. It's very, very strict diet, it was. I always remember, you could never eat a full slice of bread - you had to cut it up!

- (3) You could only eat three quarters. And you had portions - everything was in portions. I don't know whether they still do it like that now, 'cause... I still go on portion rating, because I can work mine out with portion rating, but yeah.

Give me some examples, then, of your diet and of portions.

Portions: right, I use ten grams of carbohydrate as a portion - I don't know whether other people do that. So, like, if I want to cheat, which I do all the time, I'll look on the back of the contents. Say, if it was a chocolate bar, I think "oh, I want a chocolate bar or I want a couple of biscuits", and I work out how many biscuits make a portion, and then I work it out that way. And I know a slice of bread, now, is a portion and whatever, so if I've got twenty five portions a day - which seems an awful lot, but when I was eleven I was on twenty five portions a day - it's staggered throughout the day, so it's giving you a balanced diet, really.

Did you have to change completely the kind of food you ate when you were eleven?

Yes. I couldn't eat crisps, I couldn't eat nothing salty, I couldn't eat a lot of bread, I could have no sugar at all, no sweets, nothing. And that's terrible, because all your friends are having sweets, and - I mean, I've come from a big family - your brothers and sisters are eating this and you can't eat it, everybody's having a slice of cake or a slice of bun and you can't eat it. And you're just sat there, and you're thinking "why me?", you know. You sit there, and I think from the age of eleven till now I keep asking that question "why me?". You know, "why wasn't one of the others have got something, why is it me?" kind of thing.

How did your family deal with it?

Well, they just accepted it. My Mum, she did like auxiliary nursing, so I think she used to think she was the sister of the ward when she was looking after me. And it was "you've got to do this and you've got to do that, and you've got to do...". And they were all strict, you know. Like I'd be sat next to Michael and he'd have a packet of crisps, and I'd go "Michael, give me one of your crisps", and, you know, try to sneak one. And Mum used to see you and she'd keep shouting at you and... It was very strict, it was very rigid.

What else did they teach you in hospital?

Like how to give injections. They taught me that on an orange. You had an

orange, and the pores on the orange was supposed to be like the pores on your skin. But all those years ago, it wasn't these disposable throwaway nib-top needles, then. Oh god, we had those stainless steel metal things that we used to have to put in methylated spirits. Oh god, they were horrible. And the needles were so thick. They used to bruise your legs terrible.

And this was 1978?

Yeah, it was. They were horrible things. You had to sterilise everything. And the way you used to do your blood sugars... not blood sugars - you didn't do blood sugars then, you used to do urine sugars - and it used to be like a little chemistry set. And you used to have to use a pipette and mix your urine with water and put a Clinitest strip in, and, oh god, it brings back memories that does.

Did you start doing that in hospital?

Yes, you had to learn how to do it yourself. You couldn't rely on your Mum to do it or your Dad to do it. You had to do it, yeah.

And were there other children with diabetes in the hospital?

When I was there, there wasn't actually. It was like a mixed ward. They all had things like asthma, eczema and whatever, but I didn't meet anybody with diabetes when I was in there at the time, no.

Can you remember if you'd heard of diabetes before you were diagnosed with it?

Well, funnily enough, my Mum and Dad were talking about a friend of the family - they call it sugar - "so and so's got sugar". And I was in the kitchen, and I was going "what's sugar?", and that was all that I'd heard about it. And then my Mum said "you know you were asking about sugar? Well, that's what you've got - you've got sugar", and I was thinking "oh, okay"; it was just like that kind of thing.

(4) And can you remember what insulin you were on?

I believe they started me on Actrapid and Monotard. Was it Actrapid and Monotard? I think it was that; I'm sure it was... or was it a long-acting one. I'm not sure. Actually, I think it might have been Mixtard. It's something that you had ten and eight - I think I had ten in the morning and eight on the night. Yes, it was a mixed one; it wasn't one that you'd mixed... no, and then I moved onto Monotard and Actrapid, yeah.

And have you any idea why you were in hospital for so long?

I think it was just the bog-standard thing that they did to teach you all the ins and outs of it at that age, because everybody reacted differently to it. And I think if something did go wrong, it would happen to me, actually. So, I think they could tell that I had... I think my blood sugars were very high to start off with and to bring my blood sugars down, so they kept me in a bit longer.

Can you remember what the reactions were of friends and neighbours when you came out and said you had diabetes?

Nothing, really. It was like... I don't know, I felt a bit like a monkey in the zoo. Everybody was looking at me and prodding me and going "oh, so what's different?", "oh, it's a shame, it's a shame", "oh, you can't do this or you can't do that". And it was like "but I'm still the same person", and they didn't see me as the same person; it was like I was like something completely different. I always remember an experience when my blood sugar was high for some unknown reason that day, and there was some sugar on my arm. And I don't know how this sugar got on my arm, I just don't know how it did, and I says "ooh, that's what's made my blood sugar high". And my brother said "that can't make your blood sugar high, silly", you know, "it doesn't do it like that", kind of like. And then I started to realise that it was the sugar in your blood, it wasn't just the sugar that you'd eaten. Because the way that they describe it to you in hospital is completely different to how you actually learn about blood sugars, you know, kind of thing. They say like what you eat, but then you just think it's sugar. I believed it was just sugar that I was eating, like put sugar on my cornflakes or sweets, they'll make my blood sugar high. I didn't realise it was the food that I was actually eating until I'd came out of hospital and I says "oh, is this sugar making me high?", and my brother says "no, it wouldn't happen like that, it'll come out in blood". But it was a learning curve, it was a big learning curve at that age. It was a lot to take in and a lot to be accepted with as well.

How did you cope at school?

Well, I started a new school, so I could get away with murder. I would get away with detentions and being late, because I hadn't had my insulin on time or I had to go back to have my insulin on time. I could get away with a lot of things when I was in senior school. Yeah, I remember that very well.

How did the teachers and pupils react?

They didn't really say

- (5) much. I mean, I remember I went on a school trip to Italy and I took my insulins with me. And they were very good and they made sure that I had my insulins and at time. But I think you grow up a whole lot quicker when you've got something wrong with you when you're young. So, you're responsible for your drugs and taking them, and if you're not mature enough to do that, I don't think they would allow you to go. So, I was quite mature to look after my drugs, and yeah, it was okay, yeah.

How did your diabetes affect your family life?

They just treated me the same, it's just that they were careful about if they hit me or something, you know, playing about and slapping and whatever, 'cause I'd say "you've hit me on my injection site. Oh, I'm going to have a bruise", and, you know, I could play up to it. But no, they were all right. As long as they didn't have to have an injection, they were all right.

Did your parents worry?

I suppose they did - parents do, don't they? But I think more my Mum than my Dad, because my Dad would switch off to it, whereas like... he knows... he's probably concerned, but he's not going to fret about every move that I make, like my Mum would. My Dad says "oh, she's young, let her play, let her enjoy herself", like whereas Mum would fret about it a little bit.

Did it stop you playing and enjoying yourself?

Not really, not as... you know, we'd go to the park and play cricket and football and that. But as I got older into teenage years, things that I wanted to do and go out and places I wanted to go, it put a stop to that, because even though drugs weren't as wide open as it is now, it wasn't the 'in thing' to go to a disco with a syringe in your bag, you know. When you get your bag searched, you know, it wasn't the 'in thing' - it's quite embarrassing. So, I could never go to stay out at a friend's overnight. I'd have to go to come back to get my insulin for the next day, so that was quite an embarrassment at times.

What about pubbing and clubbing - did you do all that?

I did if I could go out with my brother. If I went out with my brother, I could go out, but if I didn't go out with my brother, I couldn't. It was one of those things - "if Michael's with you or Colin's with you, you can go out, but if they're not with you, you can't go". So, that was a bit restrictive, but I was a bit rebellious, 'cause "just because there's something wrong with me, I can't go anywhere", so they'd get that thrown back in their faces quite a bit. But I was a very angry teenager, because I hated having this diabetes restricting me from doing what I wanted to do. So, I'd make everybody know that it wasn't my fault, or they'd pay for it because I'd got it and they hadn't got it. Very nasty with it, I suppose, looking back at it now.

Did people who knew you then say that that's true?

Oh yeah, they'll say it's true, oh yeah. "She was horrible, she was. She's miserable and she's horrible" my brother

- (6) would always say. "She was always sick with something", you know. They always say something like that. But no, it's just one of those things, I suppose. They just saw it as me growing up and me with diabetes, they didn't see it any different. I mean, they looked out for me - well, they had to, they were my brothers and sisters - but, you know, it wasn't them. And I always believe - it's not them, it's me. It's me that's got to put up with this, and, you know, you look at it and you think "why is it me?" kind of like, which, I suppose, a lot of people do wonder when they've got it.

Did you do much drinking or drugs as a teenager?

No. I used to drink Martini Bianco, I remember that, but I didn't do drugs at all, no. I thought, I've got enough drugs going into my body, and it never, you

know, took over like... well, why do drugs, you know? You get high when you get a hypo; you don't need anything else!

And how strictly did you keep to your diet at school and in your social life?

Fairly all right, until things started to go wrong, and then they says that I was doing this and doing that, and I wasn't. And I thought "well, stuff it". If they say that I'm doing these things and I'm not doing it, I may as well do it. And it doesn't work. It just leaves you with loads of other things wrong with you, so, you know, you just relate back to... you seem to fray from it, but then you go back to it.

When did things begin to go wrong?

Oh god, I must have been about seventeen, eighteen. I used to get a lot of abscesses. I used to get perianal abscesses, which were very, very painful, and I'd get abscesses on the legs as well. I've got something called *Staphylococcus aureus*, so. I wanted to be a chef, and when they found out I'd got *Staphylococcus aureus* I couldn't do it, because you can't do cookery and have that virus in your body, so that put me off doing that a bit, but. And it was hard to stand up as well, because you've got boils on your legs constantly, and it was horrible.

And who began to tell you this was your fault?

My fault?

You said that people said that it was because you hadn't done the right thing.

Oh, the doctors. But I'm one of these diabetics that what will go wrong, can go wrong, has gone wrong, and it's tough, you know. I get something that always goes wrong, and half the time I've not done anything, you know, to start it off, to trigger it off, but I just have things that go wrong. It's just, that's the way.

But, as a teenager, that then made you think that there was no point in being strict?

No, no point... You could cheat a bit, but you know that if you went over the top, you'd end up in hospital with some kind of high blood sugars or change your insulin over or something, you know, so. But I did try very hard to stick to my diet and that - I did; I did try

(7) very hard.

Did you have many hypos as a teenager?

Yes, I did. I remember I was staying with my aunt and uncle in Bearwood, and I was playing in the park as happy as day, and the next thing I was in the hospital waking up from a hypo. It happened to me quite a few times - I'd be playing around, and then all of a sudden I'd be waking up and I didn't know what had happened. Yeah, very embarrassing that, especially when you're like seventeen, eighteen - it's very embarrassing. I think that's why my Mum and Dad put a

restriction on who I went out with on a night, 'cause I could flip into a hypo like that, quite quickly.

Can you remember what attitudes were to diabetes among other teenagers?

Well, I thought "well, as long as they ain't got it, it's all right", that's all that mattered, you know. They weren't... it wasn't like you've got some incurable disease, like what it is. It was just like, "well, they ain't got it, it don't matter, does it?", you know. It's just one of them things, 'cause it didn't come quite popular with children up until about ten years ago, did it? So, it's just one of those things. I mean, there was a boy at school that had it as well - Christopher, I remember... I think his name was Christopher. He had it as well, and I used to say to him, you know, "have you took your insulin?", and he'd say "yeah, have you took yours?", I mean... But, we spoke, but we were distance speakers, like we didn't want people to know that we'd got the same thing, kind of like, but yeah. But it was good to know that I wasn't the only one that had got it.

But only two of you in a large comprehensive school?

That we knew of, yeah.

Did you have any boyfriends?

I did. They never lasted long, because if they'd seen me going into a hypo, it scared them, absolutely scared them, and they went "oof". Yeah, but...

Can you remember any occasion like that?

Not directly off, but I know that my illness did scare them. They says that they could cope with it and it wouldn't be a problem, "you'll be all right". And they were all right until you were sick and in hospital, and you've got tubes going down your nose or something, and then they'd think "god, she's really, really ill", and then they run off, kind of like. They don't want to know, so. Yeah, it is very scary.

(8) You say that you were not able to be a chef. Did your diabetes determine in any way what you did when you left school?

Yes, because I was always ill with these abscesses and things, so I had to sit my O Levels in hospital, and then I went on to do my A Level English and History, but I couldn't actually sit the exam because I was ill at the time, and they wouldn't let me sit them in hospital again. So, it determined what I did with my life. And after being in hospital, going to college, being in hospital - it puts you off doing whatever you want to do. And I didn't want to do anything in nursing or anything around a hospital, because I'd had enough of seeing a hospital - I was forever in it, I didn't want to work in one as well. So, yeah, it did have a... what I did with my life. But funnily enough, I left school and college, and I worked in an old people's home, funnily enough, for a couple of years. And that was all right, but I saw more people with diabetes there, because the older ones had it. I was a good little worker, I enjoyed my work, but then I was never really happy because the diabetes took over again, and that's when I started



to get ill with my pancreas, and they found out that I'd got gallstones. They'd popped over into my pancreas, and I'd got a cluster of gallstones in my pancreas. And I worked for four years with this pain, and they couldn't find out why I was getting this pain. It was a chronic kind of pain, a really acute pain. It was... I don't know what I'm saying here - chronic, acute - it was terrible, the pain was terrible. And I went to doctors and doctors, and they says it must be in my head, because there's no way that I can get this pain if I don't take drugs and I don't do this and I don't drink. And it was terrible; it was absolutely terrible, but. When I was about twenty two I had to have my pancreas taken out, yeah. They left the little bit attached to the spleen, but yeah, that was a horrible experience. It took a year, a whole year to get over that. It was a big, big operation - seven and a half hours.

How long were you in hospital that time?

Oh, good grief - about six months, I think. I was in hospital a long time.

Now, this would have been, if you were twenty two, about 1989? What were hospitals like in 1989?

Grotty, really. They were horrible places. But, I mean, they were clean. They were more rigid - I mean, you had strict visiting times and stuff like that, so you couldn't... like when we was little, you couldn't see your parents all through the day, you know. You could only see them at seven o'clock on the night, seven till eight o'clock for an hour, and if they came late, you'd see them less time. It was horrible, very strict, very 'can't get out of bed', very 'you can't wander down to the shop' like how you can now, it's... yeah, very strict.

And it was still very strict when you had your pancreas out?

Yeah. Very different to hospitals today, yeah.

Where was it that you had your pancreas out?

City Hospital, on the surgical ward, yes. I never thought I was going to live after that operation, because they'd cut me right across my stomach, and I never thought it was ever going to heal and I was ever going to get better, and oh god... Then I had to go back and live with my Mum for a whole year after that. I remember having a settee, a makeshift bed, like one of those sun beds in the lounge downstairs, all padded up for me to lie on, and then go upstairs to my bed in the night, yeah. And I remember her teaching me to walk round the garden to get me strength up, so that I could actually go out shopping and that, yeah.

Had you been living away from home before that?

Yes, I'd left home when I was... I think it was twenty... twenty, yes. I wanted to live the high life!

Had you managed to live the high life?

Well, I moved in with my boyfriend. I had a boyfriend at the time, and we moved into a flat together, and it was all right. It was while I was working, he was working. We had a nice life, but then the pancreatitis started, and he couldn't cope with that very well. He could cope with the diabetes and the hypos and the high blood sugars, but he couldn't cope with the pancreatitis at all, 'cause that was just constant pain all the time, yeah.

- (9) How do you feel about the fact that you lived with the pain for four years before it was diagnosed?

Well, when you've got a pain like that, an acute pain, and people are telling you constantly that it's not there - you've been to numerous doctors and they're telling you it's not there - you learn to believe that it's not there. And you actually work through this pain. I mean, it doesn't matter how many times I was sick a day, how many times I was sent home from work crippled up in pain - you'd told yourself that the pain wasn't there, and you worked through it. I was very angry when I found out that I had got a stone, but also relieved, because I thought it was in my head. I thought it was all in my head that they hadn't noticed this pain that I was going through. And when you're constantly told that the pain's not there, it does actually frighten you, because you want to know "well, what is it then?", "am I going mad?", you know "what is this pain here that I'm getting?", and nobody can see it. But it was just one x-ray. It was just a normal x-ray that they did, and they held it up to the light and they could see the cluster of stones in my pancreas, and they says "that's what's causing your pain". I was just... I was relieved, I really was. I could have kissed the doctor when he told me, I really could have. I was so pleased to know that.

Can you tell me a little bit about your relationships with doctors and nurses over those early years, say up until you were twenty two?

Oh, they used to think I was arrogant, because I just didn't... My philosophy with doctors, or what stressed you with doctors was... how do I say it - is that if I don't speak to the head doctor, I'm not speaking to anyone. Because you end up being pushed around from head to toe, and they tell you ten different things, and then they have to go back and talk to the head doctor in the first place. So, my theory is: go to speak to the head doctor in the first place. Get it from the horse's mouth and then do what they want to do, and then if there's anybody querying it, they have to speak to the head doctor.

You've learnt that over a number of years?

Oh, yes. I mean, they send me to clinic now, and they say "well, you see Dr so and so", and I say "no, I will see Dr... the head doctor. If I'm not seeing the head doctor, I don't want to see anybody". And then I'll just say "I'm going home", and I get up and I go. "Oh, no, no, no, no, no - wait, wait, wait, wait, wait. We'll put you through".

How have you got on with nurses over the years?

I don't really bother with nurses. I mean, you have your dedicated diabetic

nurse or your delegated renal nurse. Well, you really have to get on with those, because you have to tell them what's what. But they're all right. I mean, you get on with them. If I don't get on with them, they have to go. I have to get someone I can talk to. If I can't talk to them, then there's no point in them being my nurse at all.

What do you mean "they have to go"?

They have to go; they have to find somebody else! It's as simple as that, they've got to go!

Were there specialist diabetic nurses around when you were first diagnosed?

No, there weren't. Those came about ten years later. They did try hard, but then they tell you all the things that you know already and you know you're not doing, so, you know, sometimes it's like "yeah, whatever". You just say "yeah, okay, all right - brilliant", then you go home and do what you want to do anyway, because they're just telling you stuff that you're not going to do anyway, so.

Give me some examples.

My one at City, she makes me laugh, 'cause she always says to me "now, have you checked your ketones?", and I'm thinking "how often do I wee? I can't check my ketones". "Oh, well, do your ketones from the ketone blood machine". And then the one doctor says "there's no point in doing ketones from a ketone blood machine, because it's going to be higher than doing ketones normally". So, we have this argument every time I go. "Oh, yes, I've checked my ketones", and I just tell her yes, and I haven't done it really, but.

Is it important?

I don't think so, it ain't killed me yet! I don't think so at all.

(10) Now, we left you lying on a sofa at your Mum's for a year after you had your pancreas out. What happened after that?

I moved out. My brother had a flat that he says I could come and live with him, so I moved out. And then when I moved into the flat, he moved out, and I lived there for two years on my own. When I was at Mum's... I was with Mum for a year, up until I was twenty three. And then, even though Dennis was finding it a bit difficult to cope with the diabetes and the pancreatitis, we tried it again for a couple of years, back at the flat, which did work, but then towards the end of the second year, it was just no go; it was just too much. And I felt completely different about the way that I lived my life and what I wanted to do with my life, because it was like a scare, 'cause I... I felt like I nearly died when I had my pancreas out. I mean, I was in intensive care and everything for a while, so I wanted to live my life the best that I did. That's when my brother decided that I could come and stay with him at his flat, and I did. And I stayed with him for a year or so, and then he moved out. Then, when he moved out, I stayed in the flat for a couple of years on my own, and, you know, just partied with the girls, went out, had a good time, went to work. I had... it was quite healthy

for that... I mean, I didn't have no problems, really, with my diabetes or my pancreatitis, or anything like that. I was quite well at that time, and that's when it was coming up to me being twenty seven. That's when I met my child's father, and we had a... we knew each other for about a year before I got pregnant, and he got very, very scared, because obviously the doctors were warning me now that being pregnant was going to have an effect on my kidneys. And it did frighten him, and he couldn't cope with that very much. And I remember a time when I had a diabetic hypo, and he was absolutely petrified. And I don't know why he was so petrified, because he was an ambulance man - his profession was an ambulance man - but he was still really scared when I had a hypo. And he phoned me Mum, and my brother and my sister come rushing down and got me out of it, and oh yes, it did scare him then. And then when he found out that I was pregnant, I suppose it scared him even more, so the relationship got less and less and less. But it's just one of those things that happened. But Reece - being pregnant with Reece was a difficult time. I spent most of my pregnancy in hospital. Yes, because I remember when I found out that I was pregnant, I'd just had all of the x-rays and that to make sure that my pancreas was still working properly and that. I'd had a bad attack of something - I can't remember what it was - because, even though you have your pancreas out, you can still have reoccurrence of pancreatitis. And I'd had a bout, and they'd made sure that they'd x-rayed me right and that to make sure that Reece was

- (11) all right, because then they found out that I was pregnant, and the x-rays hadn't affected Reece, and oh, it was a tiring time. But they looked after him very well - they looked after me and Reece very, very well. We had first class treatment - I can't complain about the treatment we had.

Was this at City Hospital as well?

Yeah, this was in the maternity department at City Hospital, yeah. I had my own little room, and I sat there, and scans every other week, it seemed like. And they kept a great eye on him - yeah, made sure that he was perfect baby, yeah.

And what had you been doing in the way of work during your twenties, after you had your pancreas out?

I worked as a care assistant for a certain amount of years, and then I had a fall at work and I had an hernia come up in the wound of the pancreas. That was what I was in hospital for - I had a hernia come up in the wound of the pancreas. And I had to go in for the scans and checking up and have that pushed back. And then I couldn't lift any more, so then I went into the admin side of it, and then I worked up to a fourth officer, and then I did the admin side in a nursing home. And then I left the nursing home and moved into the admin side of social services completely, so then I was known as a personal assistant to one of the managing directors. So, I had a nice job, a cushy job. I enjoyed it very much.

You said that you felt you nearly died when you had your pancreas out and that changed your attitude to life. In what way?

Well, I just thought, well, ever since I was eleven, it seems like my life's been shortened, and I'm not going to have people telling me what I've got to do and being ordered around. I'm going to live my life to the best that I can do. I mean, not put it in jeopardy, but live it to the best, and that's what I've done ever since. I mean, there's always something's dragged me down or pulled me back into reality, but I don't go over to the extent; I just live my life.

Now, what happened after Reece was born? Did you breast-feed?

I didn't like it. He doesn't like milk very much, so I only breast-fed him for about a month, I think it was, yeah. He was a good baby. He was born premature, actually; he was six weeks premature. Yes, he was a bit of a nosy boy - he wanted to come out a bit early, and he was in ITU for a week. But I was ill after I had Reece, because I lost a lot of blood, and I was very ill after I had Reece. But pulled myself back up, and yes, the two of us have been together since, yes - my little prince.

And tell me what it's like to be a single Mum with diabetes.

You're just tired all the time - just tired and snapping and tired all the time, but he's wonderful. I mean, he's never known anything different, so he's known that Mummy's got diabetes, and he knows when Mummy's having a hypo to go and get the Lucozade, and he knows that Mummy's got to eat, and Mummy must eat with him and stuff. He's wonderful. It's just that I get very, very, very tired, but I think that's got to do with the renal dialysis as well, not just with the diabetes. It really does tire me out. And I've not been able to work since I've been on renal dialysis at all - I just haven't got the energy.

(12) When did you go onto dialysis?

I think it was in the year 2000. It was just as I was about to finish the second year of my HNC at college, yeah. And I found that I was filling up with fluid and I couldn't breathe. I just couldn't understand it, because I was on a high dose of water tablets, but they just weren't working at all. And when they took me into hospital, I found that my kidneys were working ten percent, so obviously that's just not enough to take the toxins out of your body, really.

So, what did they say to you?

Well, they introduced me to a form of dialysis called CAPD. It's when you have a capillary tube into your stomach, and you put the fluid into your stomach - it's the same method as osmosis - and it takes all the impurities out, and then you drain that out, and then you drain fresh fluid in. And you do that four times a day, but it's very, very, very tiring - it didn't agree with me at all.

Did you do that at home?

Yes, you could do that at home. That's when my malabsorption really got going, it really got going, and my albumin reduced. My albumin went right down to eleven, which is critical, really - it's just like you've got anorexia or something like that. And they found out that they had to give me albumin through a drip

to try and build it up, but it wasn't building it up. So, towards the end, they changed the dialysis on to haemodialysis, but that was also after I caught a bug; I caught peritonitis. I went on a mini-cruise to Spain, Bilbao, and I must have caught a water infection from the water on the boat, and it kept me to have peritonitis, which I was seriously ill with. I nearly died with that - five years ago now; it was five years ago now. And they took me to the QE, where it was touch and go for a couple of weeks, and then they put me onto haemodialysis, which, touchwood, it's been working since; it's not been too bad. It just leaves you very, very tired, very tired, and you have to keep in touch with your diet. Your diet is absolutely... you know, you think you've got a diet with diabetes. You've got... I mean, I'm on so many diets now - I'm on a diabetic diet, then, because they took my pancreas out, you're on a low fat diet and so you can't eat many fats at all, and then now you've got your dialysis diet, which is low phosphates and

- (13) low potassium. It's... you know, people like you will say "well, what do you eat?", you know. I eat the same as you, but it's the way that I cook it. It's, you know, I can eat mashed potato, but I've got to boil my potatoes twice to get the potassium out. I can eat vegetable bake, but all my vegetables have to be boiled twice. I can eat cheese, but low fat cheese, and, you know, it's not difficult to do, but it's just the way of life - the way you make your life to adjust to these diets, really. And you've got to adjust to the diets, otherwise it's going to kill you. Because, if you have too much phosphates and potassium, it affects your heart, and if you have too much fluid, as well, with the diet, that affects your heart as well. So, your heart is the engine of your body - you've got to protect your heart by all that you eat and do.

Have you managed to do any paid work?

Since dialysis? No, I haven't. It kills me. It's amazing I'm up now talking to you, to tell you the truth, because normally I'm in bed, because I dialyse late on the evening, so it usually zonks me out the next day. But yeah, I'm just unable to look after Reece and do paid work as well; it's very hard.

How have you managed to fit in looking after Reece with being admitted to hospital first, when you had dialysis, and then with all your trips to hospital now?

Well, at first Mum looked after him, because Mum was much younger then. Mum looked after him, and I've always had a childminder with Reece, ever since he was six months old, and he calls her Nanny Ruth; he loves her to death. And when I was having dialysis at home, she used to look after him. Every other day she used to keep him overnight so that I could have a rest, because it's very, very, very tiring. And then, when I went into haemodialysis, we've made arrangements through social services, now, that he can stay with her whilst I'm at dialysis, and then he comes back home to me when I'm at home. So, it's quite acceptable and he likes it, and he keeps the same routine so that he can adapt

to that; he can adjust to that.

And how much energy do you have for him?

Not a lot, and he's one of these children that'll whiz around twenty four hours a day, all day. He gets up at six o'clock in the morning and he goes to bed at nine o'clock at night, and he's up... and he doesn't have a nap in the day or anything. He's on the go all day long; all day.

- (14) We do find that we have special times, me and Reece. We refuse to answer the phone on a Tuesday, Thursday and Friday night between six o'clock and nine o'clock. That's our special time, and family and friends who know me, know not to phone at that time, otherwise it just go onto the answer machine. Because, I find that like friends who haven't got children, they want to talk to you, and they want to talk to you when you're not on dialysis. And obviously, if you're not on dialysis, you're at home, and when I'm at home, I want to spend that time with Reece. I don't want to be talking to you about the colour of your carpet or what hairstyle you've had, I want to be spending time with my son. So, I refuse then to talk to my friends until nine o'clock, and if they're true friends, they'll call you after nine o'clock, really. I spend time with Reece. We usually make something once a week or we paint something, or do something together, so that, you know, we spend quality time together. Even if it's watch a movie together, we do something together.

What sort of thing do you make or paint?

Oh, we used to paint... I don't know, we just... "do you want to paint a rainbow?" or "do you want to paint a topic?" or "shall we paint a plant?" or "shall we make something?" or "shall we build something?" or "shall we play a game or something?". You know, we spend time together. He's getting big now and he's going to rugby now, so he's out at rugby at least a couple of times a week, so it keeps him active as well.

And for the benefit of anyone who may have to go onto haemodialysis, can you explain exactly what it's like going to the hospital and everything that happens?

It's very tiring and it's very time consuming. I do two twilights on a Monday and a Wednesday, and an afternoon slot on a Friday. If I didn't do an afternoon slot on a Friday, I'd have no energy for Reece at all come the weekend, which I find is very important. Now, the ambulance, unless you drive yourself and you can take yourself there and back, which I don't, you have to wait for the ambulance. It can come any time between five and seven o'clock on the night. You can get to dialysis at five o'clock, but you might not get on a machine till seven o'clock. You're on a machine for four hours then, so you don't get off until eleven o'clock, and by the time they've bandaged you - well, plastered you up and whatever - it's twelve o'clock before you're home. It's a very, very tiring night. But haemodialysis, it's like going for a day's work; it really is. It's not like you just sit on a machine, it pumps this blood out, cleans it, pumps it back. It's

very, very tiring. I mean, you imagine having your blood pumped out - seventy two litres is my average amount of blood that you've got pumped in and out of you - and, you know, being cleaned and got the fluid out of it. It does leave you quite drained; it does leave you very, very tired. But, it's a way of life, and if you have to have it, you have to have it. If you want to live, you have to have it. I mean, sometimes I get

- (15) really down and really depressed, and I say "I'm not going today, I've had enough. I've had enough, it's too much for me", but what else do I do? I could not go for a week and then I'm dead, or you pick up - you've got a son, you've got your life to live, you go. I mean, it's totally up to you what you want to do with your life when it comes to dialysis, but you'll see that in the long run, there's people that are worse off than you. There's people that are better than you, but at the end of the day, it's your choice what you want to do. And even though I moan about going, I wouldn't be without it, because I wouldn't see my family and my son and my friends, and, you know, that's a big part of your life.

What do you do when you're hanging around waiting for the dialysis to begin, or what do you do during the dialysis?

I bring a little portable telly during the dialysis, so I watch Emmerdale and Coronation Street or whatever rubbish is on. Sometimes I read a book and sometimes I can sleep through it, but to sleep through dialysis you have to know what the machine's alarming for and you've got to be able to sleep through that. It's not too bad, because you've got nurses there and they'll look after your machine for you, so it's not too bad. And whilst I'm waiting to get on dialysis, I normally talk to the other patients, because your patients become family to you, because you see them more than you see your own family. You see them three times a week, every week, the same people, so you know about their lives, they know about your lives, and it's like a little close knit family, really.

Can you describe a typical day in your life, perhaps when you're not going for dialysis, including everything you eat, so start me off when you get up in the morning?

Okay. I don't get up early in the morning at all - well, if Reece is here... okay, if Reece is here, that means I'm not going to dialysis, so it's a Tuesday morning for instance. Reece'll get up at six, probably he'll stretch it to seven if it's a school day. Reece will get up, have a wash, have his breakfast. I'll go downstairs and make sure he's got his breakfast and probably make myself a drink. He'll get ready for school, then the carer will come to take him to school. He then, he goes off to school, I go back to bed and I have a lie down for a little bit. Then my carer comes in to make sure that I'm up, I've got my tablets, because I can have hypos through the night as well, so they've got to make sure that I'm up and I'm ready. And then I get up and normally have a wash, get dressed, but I'm very tired, so I'll lounge around the house most of the morning. Then I'll have a sandwich or something to eat about one o'clock. Reece will come home



from school at three, but I normally go and pick him up on a

- (16) Tuesday, so I'll walk up to the school on a Tuesday and pick him up. He'll come home about three. We'll cook tea together - that's part of our plan . He gets dressed and we cook tea together, and then he has his tea about five, six o'clock. And then that's our time, six till nine o'clock, where we do our whatever things and sort ourselves out. That's my average day.

Do you have any exercise?

I used to exercise quite a lot, but since I've been feeling very tired and very low, I haven't done so much exercise, because I had a parathyroidectomy last year and that left my bones very weak. So, I haven't been able to exercise as much as I used to like exercise. I used to some stretches in the morning, and, you know, some things like that, but no, I don't do that much exercise any more.

You keep mentioning other complications quite casually. Let's make sure we've covered them all. Have you had any problems with eyes or feet or..?

I've got retinopathy of the eyes, but not serious retinopathy, but they like to keep an eye on it every six months at the eye hospital. I also suffer with malabsorption still, because of my pancreatitis, because you can't absorb all the foods because the pancreas isn't there. So, they have to be careful of that and encourage me to eat, but I'm tired all the time so it's very hard to eat. I try very hard to eat, but it's like a vicious circle: if I don't eat, I get tired, and then I eat, and then I've got a bit of energy and then I get tired again, so we have to take care of that. I also have something called autonomic neuropathy, which quite a few diabetic patients do have, and the cramps that I get from that is absolutely mind-blowing. I can get them... if they start on the machine - which you can get cramps on the machine anyway because of dialysis, because of the salt levels - but if they start from the salt levels on the machine, my neuropathy doesn't go for a couple of days after. I can have cramp all through the next day until I'm right back on the machine the following day, and it's quite painful, really. So, I can't exercise much due to the neuropathy because it's very, very, very painful; very painful.

How well do you think the medical staff understand what your life is like?

I don't think they understand at all. I don't think they really understand at all. I mean, the doctor that I've got now at the hospital, I mean, I've explained it all to him and he does seem to sympathise or empathise, whatever one it is, with the condition, but unless you've got it, you will never ever know what it's like.

Do you ever think about how your life might have been different if you hadn't had diabetes?

- (17) Constantly. I assure you, I wouldn't be living in England. I would have been living in Italy, teaching the Italian children English or something like that. I've always wanted to do something like that, in the sun.

What keeps you going?

My little boy. Yeah, he's just the thing that keeps me going all the time. He's my north, south, east and west. I think, without him, I wouldn't have bothered to carry on, really; I wouldn't. But he does; he makes me carry on.

Do you have any message for anyone who's newly diagnosed with diabetes?

It's not as bad as you think it is. If I can live with it, anybody can live with it. It's not that bad. Just stick to... you know, try and listen to what the doctors say, and try and enjoy your life. Don't be so strict with it that you don't live. I mean, no life's worth living if you can't do a little bit of something. I'm not saying cheat and be bad and get all things wrong with you, but enjoy your life. Life's here to be enjoyed. It's not to be like... You're not a page in a book, it's written that this will happen and that will happen - it doesn't always happen like that: my life's proof of that. But enjoy your life. That's all that I can say, enjoy it as much as you can.

You've implied that you've been told off by the medical profession quite often. Can you talk a bit more about your relationship with members of the medical profession - we talked up till you were twenty two, but say since you were twenty two?

Oh, I don't see them that much, really. As I say, I see the top doctor, and if I don't see the top doctor, I don't really want to see anybody else. But they will say "well, Patsy"... they always used to say "Patsy, you haven't done your blood sugars". And I say "I have done my blood sugars, I've just not written them down" - which is, according to them, "you haven't done your blood sugars" - until I show them my fingers and they can see the pin-pricked fingers, and they say "yes, well, you have been doing them". But now they've got this new machine that you can actually do your blood sugars on and it downloads onto the computer, and they see that you do it, so I'm quite happy with that, so I don't have to write down the results. But they do, they tell you off "oh, you haven't done this and you haven't done that" or "you haven't eaten this". You know, you're not a textbook. You can't live your life by a textbook, and I refuse to live my life like a textbook. But I do do what they tell me, as much as I can, but I'm not going to live my life textbook style; I'm not doing it, no.

(18) And you've just remembered one other complication that you'd forgotten to mention.

Yes, I had an infection in the bone, not last year, the year before, yes. And they were very worried because they thought I was going to lose my big toe, but it didn't happen because the infection cleared up. I had to spend a month in hospital on IV drugs, which is absolutely terrible, because when you're a renal patient, you've got no vein - your veins narrow very, very thin. And to get an IV into me for a month, it was like changing the position every other day, and I was just black and blue literally all over from trying to get positions to get... But it did, it happened, and we managed to save my toe, yeah.

And what happened to Reece while you were in hospital for a month?

He was going to the child minder's and to my Mum's, yeah, 'cause they were both in the country at the time, so, yeah. And he came to visit me once a week. We tried not to get him down too much to ruin his work regime, you know, how he was working at school, but he'd get very upset if he didn't see me, so, yeah. At the weekends, he used to come down at the weekends.

Do you have any regrets in life?

I do with having diabetes. I regret that I was the only child out of my whole family that's got diabetes now. I mean, thinking about it logically, Dad has got mild diabetes now, but he's just taking tablets. But he's only had that a couple of years, and he's sixty seven now, so I can't really say. . . I think that's just type two diabetes, I think. But I regret not being able to live my life the way that I would have wanted to live, travel more - I'd have loved to have travelled more. I'd have loved to have been a chef and travelled the world doing those things, and if not, I'd have loved to have gone to live in Italy or France or somewhere and taught children a different second language. I'd have loved to have done all of those things, and it seems like, because I was ill, I've had to restrict it. But if I was a bit more ambitious and a bit more daring, I suppose I could have done some of those things. But now, with having the haemodialysis, it's very difficult. It's not too bad in Europe, but to travel to the Americas and Australia and places like that, and to have to pay for all of your treatment, it's very, very difficult. I think, once you've found a good doctor, you need to stay with a good doctor and good nursing staff, because you just don't know what's round the corner. But that's the only regrets, that I didn't do more before I got worse. But it's not saying that everybody will; it's not saying that. I mean, you could have had diabetes from eleven and you've not got a problem with your kidneys, you know. You could have had six kids and you've not got a problem. But it all depends. . . I always say, it's what's in your book of life, and you live what's in your book of life. I mean, that's the only regret, that I didn't travel more and see more of the world, but I'm very happy. I mean, my life is happy. I've got my son, I've got a nice home where we live together, and we enjoy our life, so I can't really say more regrets. . . that's not a regret, that's a positive.

How do you see the future?

I take the future one day at a time. I don't plan it no more, because nobody knows what's round the corner. I refuse to make big plans and then let down. I can't make plans for Reece, because I don't know whether I'm going to be well one day from the other.