

(1) Tell me about your background.

I was born in 1972. My mother's name is Mary and my father's name is John; we did actually lose him a couple of years ago. I have a sister called Lisa, and she's eighteen months older than me. My Dad was the owner of a furniture shop for many years - as far back as I can remember, and my mother was actually in childcare in Social Services. We didn't, admittedly, see a lot of her as children - she did work a lot of nights, so it was left to my Dad, really, to bring us all up. Both very hard working and extremely supportive of when my condition started. My sister, pretty much the same: very supportive - we are very close, and she does actually suffer from an autoimmune disease herself; she suffers from MS. So, it's been a big learning process for all of us, really, but we were a very close fam... or are a very close family.

Would you say that you were quite well-off as you were growing up?

Not particularly, no. It was a struggle for many years for my Mum and Dad, and they did the best they could. And really... well, we were a very hard working family - we still are - and no, I wouldn't say it was the easiest childhood for money, but we didn't go without, so, you know.

Tell me what your memories are of being diagnosed with diabetes.

Well, they are actually my earliest memories. Admittedly my first memory is actually waking up in hospital when I first went into a coma, but I do recall being very poorly for a few weeks beforehand, and the worst thing being extreme thirst, stomach aches. I was taken to the doctor several times, and we were actually told it was growing pains, which is a shame! But, from what I can remember, it wasn't anywhere near as widely recognised as it is now, but it was a very traumatic time. I can remember getting up in the middle of the night drinking anything I could get my hands on: neat squash, cream, anything - I was so thirsty. And my Dad used to find me in front of the fridge, early hours of the morning, and I used to be told off very regularly. But, of course, my father was actually part-time St John's Ambulance, and he did have an idea of what it may be, and, of course, was very worried.

(2) And eventually I was very, very poorly the one day, and it was my sister that came into me during the night - heard a lot of sort of movement and moaning and groaning. And my father realised that I was actually in a coma, and he did all he knew, and that was to rub sugar on my gums. And it's quite a touching story, but it was my sister that called the ambulance, at the age of six and a half. She wasn't told to do it, and we were told later on that it was a very wise move on her part as I was so poorly when they took me in. And I do remember waking up quite a while later while I was being connected to a drip, and, you know, being fussed around by doctors and nurses, and, of course, I was very frightened.

How old were you?

I was five years old. Still obviously quite young, but it's remarkable how much

I can remember. And, of course, very, very bad for my Mum and Dad as well, seeing their little girl in that state, but, as I say, it's very vivid in my mind, so.

Did they blame your local doctor who said you'd got growing pains?

I think initially out of fear and panic, but it was so uncommon at the time. Certainly we didn't know of anyone else in the area who had children that were suffering from it, so, you know, it's certainly not as common as it is now. So, yes, there was initial anger, but really the doctors and nurses at the hospital were fantastic, and, you know, helped us through it initially, so.

What happened after you woke up from your coma?

My first memory was I did actually wake up with a nosebleed, which, of course, added to the problems. And, as I say, I do distinctly remember seeing my parents in the room - very upset, very frightened also, and I can obviously remember feeling extremely poorly. But within a couple of hours of actually being on the drip, I felt quite remarkable again, and it just goes to show, you know, how poorly I was. And then the next couple of days are a bit blurry, as I remember it. But I do remember, obviously, having to be trained and talked to, which was very difficult at my age to understand.

Were you taught to do your own injections, aged five?

I wasn't. I didn't really... I wasn't too responsive at the time; I was obviously very scared.

- (3) But I do remember going into a separate room with my mother and father, and they were actually taught to inject on an orange, which is quite an amusing memory. And, of course, that was very bad for Mum and Dad, and the thought of having to do that again to their daughter. But, of course, we had to learn very quickly, and, you know, they were taught to do my injections in the hospital, and that's how it carried on. And it actually took me a couple of years to be brave enough to do my own injections, so, you know, it did take me quite a long time.

Did it hurt when your parents first did it?

Very much, very much. It was... I do remember it hurting, and I think it was difficult for them, because obviously they didn't know if that particular part of my leg was sore, or... and they did have a fight on their hands every time I needed an injection. I have distinct memories about the old glass syringes, which were huge things with huge needles. We had to sterilise them ourselves. It was all... I don't think I ever got used to it. Every time I saw that needle they used to have to sort of drag me out from behind the curtains and under the bed, so it was very hard for them, very hard.

And were you doing the sterilising yourself?

No, Mum and Dad did everything; they did do everything initially. I think they were so keen to follow the rules, as it were - you know, I didn't get involved.

Even down to the first blood tests that I used to do, they were actually... I'm just trying to think what they... they were like lances, metal lances that they had to manually stab into the end of the finger, which was not pleasant. But, of course, the way it's come along since then is quite amazing. But no, I didn't get involved in any of the initial medical stuff.

So, it was blood testing in 1978, not urine testing?

It started with the urine testing for - well, for quite a long period, and then I'm not entirely sure when the blood testing came about. I know it was a very primitive method when it did start, and I desperately tried to hold onto the urine testing rather than that. But the doctors and nurses obviously had progressed and felt that that was a more accurate way of testing the blood sugar levels, so I was politely encouraged to accept that testing method.

Can you remember anything about urine testing in hospital, or was that all blood testing in hospital?

It was all urine testing in hospital, but once a day I had to go down

- (4) to the actual blood testing unit, where they took blood samples from my arm. And again, at the age I was, I found that very frightening. But it was... my urine was tested several times a day, and eventually I do recall being trained by the nurses to learn to do that myself. I wasn't trusted wholly when I got home, because obviously there were chemicals involved, but my father used to certainly stand there while I tested my own samples, which was good - you know, he taught me from an early age to do that, so.

Was that with strips or...?

It was actually - the old urine tests were with a test tube, and I think I recall something like three drops of urine to so many drops of water with a pipette, and then we had to put a tablet into the test tube. And the only colours I tend to remember was blue, which is when my sugars were low, and orange, when they weren't so good and they were high. So, I don't have... it was actually testing against a colour chart. And we were very vigilant with that - we did that several times a day, and I do remember that very well.

How long were you in hospital for?

I'm not exactly positive, but I know it was a good few weeks initially. I know that the doctors did have a lot of trouble actually stabilising my condition - finding the right insulin and doses. And it took a while for me to get into the routine of learning to have snacks in between meals, and learning that I had to eat at a particular time when I injected, so it was quite a few weeks. And I don't think I was actually out for too long before I had to return again through a common cold, which unfortunately aggravated my condition. And although I'm not sure of times and dates, I do seem to recall being in hospital an awful lot in the first few years, so it seemed to be an ongoing thing, as I remember it.

Were your parents given much guidance about diet?

Lots of guidance. We had books and things like that; we were given a pair of weighing scales. Again, they were very strict in the beginning - we had to weigh out all of the food and that sort of thing. I found that particularly difficult, because once I was back to feeling like a healthy five year old again, I couldn't quite understand why I wasn't allowed to eat the things my sister could eat.

- (5) I missed my sweets, my chocolate, and I just felt very deprived all the time. And I always had a healthy appetite since a baby, and I just - although I could actually eat more than most people, because of the snacks I had to have in between meals - I just found at meal times that I couldn't eat what I wanted to eat. And that was very difficult for my parents, because they, you know, they felt guilty for depriving me of the things I wanted to eat, but it was very strict then, so.

Did you try any special diabetic products?

Lots and lots. I remember, at the time, the only place that we could find any low calorie pop was Boots, at the time - Boots the Chemist - their One-Cal range, which was very limited at the time: lemonade and orangeade, I think it was. And they tried me on various things: diabetic sweets and chocolate. I never did like any of them, to be honest! So, you know, they had a constant fight with me. Found me sneaking sweets and accepting sweets off other children, which obviously didn't help my sugar levels at the time. But I recall there being a limited amount of diabetic products, or certainly low calorie products, at the time, but a few years later they just seemed to appear, so I do...

Were you in your first year at school when you were diagnosed?

I wasn't... When I was diagnosed, my mother had actually enrolled me in my local school, and when they actually found out about my condition, they did actually try to stop me going there, which was very traumatic for my Mum. She had to have several meetings with the headmaster to explain that, you know, I was a little different with my condition, but it was of no threat to any other children. And people just didn't understand back then. They were concerned that I was going to disrupt the running of the classes, and it was a very hard time for my Mum to actually try and convince them that, you know, I could go to a normal school, and eventually they agreed to take me. So, it was very much on the start time of my primary school that I was diagnosed. And, of course, when I did attend school, it was very difficult.

How did other children react?

Very badly. Not fond memories for me.

- (6) The children wouldn't play with me. They used to say "oh, don't talk to her", you know, "you might catch something". That was very hard, because, of course, I wasn't totally understanding of my own condition. And there used to be tears every day, you know, and Mum and Dad found it very hard to explain to me that, you know, I didn't have anything catching. And also, I used to have to have snacks, morning break, and I

was kept in the classroom to drink my milk and have biscuits, which the other children weren't allowed to have, and, of course, I was very much targeted about that. They were quite nasty to me, and saying "well, why can you eat" - you know - "and we can't eat?". So, I didn't have many friends at school, which was difficult. I always found that I was trying to explain my condition to people, and I found it very difficult to make friends, so it was quite a hard time.

How did the teachers behave?

The teachers were fantastic. Obviously they were prepared and told that I was diabetic. Nothing happened much at school, but if I did have hypos in the middle of class then I knew I was only to put my hand up and they would deal with it. They were very good, very understanding. But, you know, again, they found themselves having to explain to the other children what was happening, and, you know, why I'd had to leave class or why I couldn't do PE. So, I think everybody found it quite hard. I was the only diabetic in the school, so.

How did the teachers deal with it if you felt hypo?

They used to take me straight to the secretary's office and they used to give me a couple of biscuits and a glass of milk, which was obviously how my Mum had told them to deal with it. And I used to sit there, you know, until I'd recovered. So, all of the teachers knew what to do, but, of course, it did cause a bit of disruption when I came back to class. So, I just always felt very much on show, and I suppose a bit ashamed about, you know, my condition and how things were going, so that was hard.

Did you do PE sometimes?

I always did PE. I was a very determined child - they'd never stopped me doing anything, but it was a learning curve. We had to learn perhaps for me to have a little more food before I did my PE lessons, so, you know, I didn't end up having a hypo

- (7) in between. But more often than not I would end up with a hypo, so, again, I could never finish a class. But I was always quite wilful and I'd always try, so that never stopped me in that way.

Did you ever pass out at school?

I've never passed out, that I can remember, from my condition. I've had a lot of bad hypos, but I've never passed out. I have come home... or I came home from primary school a couple of times quite poorly with stomach ache, and unfortunately my Mum sometimes used to think that I was just trying to get a day off school. And on one particular occasion, I did come home very poorly, and I did actually wake up back in hospital, so it was all very difficult. We had to learn about the symptoms and that type of thing, and they never seemed to be regular types of symptoms. It always seemed to be different in the beginning,

so, you know, especially when I was at school and my Mum wasn't there or my Dad wasn't there to keep an eye on me, it was a very big worry.

What was it like for your sister?

We had a very difficult relationship when I was growing up. I felt very hard done by in the first few years. I wasn't the most happy child for the first few years of my condition, and my sister and I used to fight a lot. I used to feel that my sister was being favoured, you know, to do with food and the things she could do, and, of course, she used to feel the same way: why couldn't she have the snacks in between meals and that type of thing? So, we fought a lot, which, looking back on it now, was silly, but it obviously had quite a big effect on her in her childhood as well. But she was also extremely protective of me, which has still carried on to date. So, you know, yes, it was very hard for the both of us. In some ways we had to be treated very differently from one another, and it did sort of affect the relationship for a while.

So, the knock-on effects of family life were quite considerable?

Yeah, it was. As I say, I wasn't the best patient, and as I was growing up I became more and more angry about my condition, and I was quite unstable for a few years. And I just felt, in teenage years, that it was very inconvenient, and

- (8) I wanted to be out with my friends, and I wanted to drink, and I wanted to do everything that everybody did, and, of course, I was very restricted. So, Mum and Dad had a big battle on their hands, trying to explain to me that it was important to look after myself. And, of course, I'm sure everybody goes through the teenage rebellion, and I didn't help myself in a lot of ways, so it was a difficult time; it was a very difficult time for everybody.

How often did you have to have injections?

Initially I was on two injections a day - that was in the early years, and I was very restricted. I had to eat the same amount of carbohydrate every meal, I had to eat at exactly the same time every day, and with the snacks in between meals, which sometimes was very hard if I wasn't hungry. It affected my weight. I was always quite a big child, which I was ridiculed about a lot, and very conscious about. And I had absolutely no control over what I had to eat, so that was a difficult thing to cope with. And as I got a bit older, and technology and science were a bit more on our side, they changed my insulins a few times. And I - it was just when I started secondary school - I was actually swapped onto the human insulin and the NovoPen injection. And they sat me down and said "you are going to go onto four injections a day" - as opposed to the two - but it would give me more freedom, especially to eat a bit more freely, as and when I wanted, within reason. And it was difficult to cope with the four injections, but it just changed everything remarkably: the freedom I had, you know, and Mum and Dad didn't have to worry so much about me having my injections at the right time. But again, that kind of had the opposite effect, where I became a little

bit too blasé about injection times and what I was eating, and again that was another huge learning curve, which was difficult after being set in the routine of the first few years.

So, how did you behave while you were at secondary school?

Quite badly! I've always been aware of my condition, I've always worried about my condition, but I tended to try and ignore it a bit too much.

- (9) When everyone else was taking trips to the tuck-shop, I would follow them. It got to the point where I unfortunately was having my injections sort of irregularly to cover what I was eating, rather than actually sticking to my four regular, or three regular meals. So, I had a lot of high and low blood sugars, and also just trying to fit in with the crowd. I felt that having to disappear all the time to do my injections and my blood testing was not the cool thing to do. So, I did slip back on that quite a lot, and, you know, my sugar levels and things did suffer for it. And that's really when my parents' battle started - trying to make me aware that I needed to take better care of myself. So, the secondary school days were definitely the hardest.

How did the other pupils at secondary school behave towards you?

Quite well. My friends were quite good, but again, I think ignorance was bliss. They used to say to me "oh, that means you can't eat sugar", and I would explain to them "well, yes, I can eat sugar, but it's just in a different manner to everybody else". A couple of very good friends of mine were fantastic. Obviously they were with me at times when I had hypos and that type of thing. They knew how to deal with it - that was great, but I still used to get the looks and the misunderstandings from other people, because again, in a huge secondary school that I was in, I'm still unaware of any other diabetic people there.

So, how did the staff handle it?

To be honest with you, it was a stage in my life where I started to hide it more. Obviously the headmaster and the staff that needed to know did know, but, of course, in secondary school there's a big turnover of teachers, and admittedly, in the end, I would say probably three quarters of them didn't know. And it only came out when perhaps I was having a hypo in class, which wasn't as often, and I had to tell them there and then that, you know, I was diabetic and I needed to go and treat myself. And that was very unfair on them - I think they were very shocked and worried at the time. But that was how I started to feel, that I was too ashamed to tell people about my condition because I just felt I didn't fit in.

And what was your teenage social life like?

Pretty

- (10) busy. I went out a lot. Again, you know, I think I did everything that most teenagers did. Mum and Dad were extremely strict about obviously drinking, which I did do on occasion. Fortunately, for me, it rarely did affect

my sugars, but definitely when I hit about the age of sixteen, seventeen, I decided that I didn't want to be diabetic anymore. And it was silly, because obviously I was a diabetic, but I chose to not go to the clinic for a good couple of years. And again, I was extremely worried about it deep down, but I fought against it, and I thought "no", you know, "I want to be like everyone else, I don't want this to restrict me in anyway", which, of course, it wasn't, really. But for some reason, I did feel, at that point in my life, that, you know, I didn't care about it so much. And it wasn't through lack of effort from the clinic, you know. I was nagged a lot; my parents were always very vigilant - my Mum still is. And it took me a few years to realise that I needed to get myself back on track, because certainly when I did go back to the clinic, my blood tests were not reading, you know, the most positive results, and eventually it did frighten me into realising that I needed to pick myself up again.

Did it affect your relationships?

It did... boyfriends... I had a couple of boyfriends in my teenage years. I always told them straight away I was diabetic, and they did the best they could; they were very understanding. But again, if I was out on a social occasion and I had a hypo, I always felt extremely ashamed and embarrassed, and always seemed to feel sorry for my partners, you know. I used to feel that it was affecting their lives as well, when perhaps it wasn't. But I was always very headstrong and I felt that I could cope with it on my own, and perhaps I should have involved people more, because it is nothing to be embarrassed about, you know, and there's an awful lot of diabetics out there. But I did tend to try and keep it to myself a lot.

(11) Tell me about leaving school.

Well, I left school when I was sixteen. Always had high hopes for myself but was never sure what I wanted to do. I was a very artistic person, so I decided, initially, I wanted to go to college, but for some reason I really felt that I had had enough of school, so I decided to go onto a YTS scheme at a pottery firm. And I travelled backwards and forwards to that job for a year or so on the train, which I... I felt very independent. I'd settled down a little bit then. My boss was extremely understanding of my condition, and very interested in fact, so we used to talk about it a lot. And for the first time in a long time, I didn't actually feel ashamed of my condition, so that was good for me; that was very good for me. And during my time there I actually got a motorbike, which was my first form of transport, and if my father was here today, he would say to people that's when his troubles started. And I did become a very wilful person. I perhaps got into the wrong crowd - back then it was sort of the bikers and that type of thing. I certainly wasn't a badly behaved person, but, again, I did tend to sort of put my diabetes on a backburner, as it were.

In what way were they the wrong sort of crowd?

I think more, you know, as people saw them - you know, the bikers and the



leather jackets, but we never used to actually do anything particularly. We were a nice group of people, but we were judged a lot, you know, because of the way we dressed and that type of thing. But as it happens, it was, you know, one of my happiest times of my life. I was mobile; I had my motorbike, which I still miss, and it was a really good time. And because all my life I always found it difficult - not to make friends - but to keep friends, and in later years I think I've realised that I perhaps did have a bit of an attitude when I was younger, because I felt different and I felt separated from what I called normal people. And perhaps that did reflect in my attitude. And I did find it very difficult to keep friends, so, you know, at that stage of my life, I met a whole new group of people after I'd left school

- (12) who were a lot more grown up, a lot more understanding, and I really did have the time of my life. But, as I say, unfortunately, I still wasn't too well-behaved with my condition, and still constantly nagged by my family to look after myself. And this phase did go on for some time, which I do deeply regret. I mean, fortunately I do know that - or hopefully - I haven't caused any long-term damage, but it did take me a while. I just felt like I had a life for once, and diabetes didn't fit into it.

How long did this phase go on for?

I would say probably for a good sort of five, six years. I did go to the clinic, but not as regularly as I should have done. The one thing that I used to defend myself with is "well, I still do regular blood tests". I've always done four to six blood tests a day, which is probably a little excessive to what they recommend, but that's how conscious I've always been of my condition. But the phase was too long - you know, I didn't look after myself as well as I should have done. And eventually, by the age of about twenty two, I think, maybe, I decided "come on", you know, "let's get yourself together", and that's when I really started taking a good look at myself.

Just before we get onto that phase - when your boss was sympathetic when you first started work, that was 1988, so do you think attitudes generally to diabetes had changed by then?

The adults that I met - what I called obviously adults, compared to my age at the time - were definitely more understanding, but whether... My boss did actually know a diabetic, which is the first time I'd come across anybody that had said that they did know somebody with the condition. And I just felt that the adults had a lot more of a different attitude towards illnesses and a lot more interest, as it were, whereas people of my own age were just sort of "oh well, you're diabetic. Okay - that's great", you know, it was that type of thing. So, he was very interested in my condition and he used to ask a lot of questions, and for once I actually almost felt quite proud of how I lived with it, and, you know, what I was, if that's the right way to put it. So, that was good. I

- (13) gained a lot more confidence in myself to actually talk about it, and I did find that, you know, the older generation were a lot more understanding

of it.

How were the people you worked with?

Well, there was only one other girl who worked there with me; same age as me. We were very good friends for many years, and she, again, was fantastic, very interested in my condition, so I never felt uncomfortable, even to the point where... if I used to have a hypo, I used to run and hide - perhaps go in the toilet and take a biscuit with me. I didn't have to do that there, so I felt very comfortable. And they never over-fussed either, you know, they took in what I said and understood, so.

How long did you work at the pottery?

I worked there for just under two years, and then my YTS scheme finished. They did ask me to stay, but I felt I was ready to go onto bigger and better things, and perhaps a little more money, so I then found a job in Worcester at a giftware firm. It wasn't my ideal job. It was very repetitive work and it was a big factory environment, and unfortunately I did find myself slipping back into the worries of hiding my condition from people. You know, some people there were nice, but they weren't the friendliest bunch of people, and we tended to sit in different rooms and keep ourselves to ourselves. So, I found myself slipping back into this routine of hiding things from people. And again, I think that caused an attitude change in myself, and I think people responded to that, so, again, I had quite a lonely-ish time at work.

Now, moving onto when you say you were about twenty two and you began take yourself in hand. What do you mean by that?

I just... The very last trip that I had made to the clinic, I was told off a little by the doctors, which wasn't unexpected, and I realised that my sugar readings were not as good as they should be. I sat and talked to them. They were very understanding, and I told them how I felt, that, you know, I felt it was affecting my life - it was a restriction on my life. They were very understanding, but obviously very keen for me to get myself back on track. And it had been an awful long time since I'd actually changed my insulin, so they

(14) took a good look at, you know, my readings and that type of thing, and decided that it might be a good idea to change insulins, which I did. Again, it worked well, but as well as I would let it. With all good intentions, you know, for the first few months everything was great, but then I seemed to slip back into this trap of just ignoring things again. And, as I say, it was my own silly mistake, and it just kept happening on and off, so. But my condition was never badly controlled, but certainly could have been better, so it was when I really started to realise, or tried to take a bit better care of myself, anyway.

Can you remember what the new insulin was - this would be about 1994?

Oh gosh... I honestly cannot remember the names.

You were still using a NovoPen?

Still using a NovoPen. I believe I was still on Actrapid insulin, which I was on for a good many years, right from the beginning, and then a different insulin in the evenings, which, I have to be honest, I have forgotten the name of, because there's been a few. I really don't recall.

(15) And how long did you stay in this 'not very friendly' factory?

I was actually at this factory for twelve years. I did feel a little trapped. I did actually get my own mortgage at eighteen, and I suppose it's a trap everybody falls into, that they think "well, I'm earning this wage every week and I should stick to what I know", which is not the best thing. But after about ten years, I did actually meet my husband, who'd... he was working at the same factory for fifteen years, and, you know, we got on very well. Realised I'd met my soul mate, and he was actually the person that I ended up marrying and I'm still with now.

What year did you marry?

We married in 2001 - if I get that right... no, sorry, 2002 - May 18th. We hadn't been together that long, but we had known each other for a good many years, and it was a wonderful wedding. But unfortunately, a year, or almost a year before we got married, we did lose my father very unexpectedly to a brain tumour, and that was possibly the worst period of my life, understandably. It had a terrible effect on all of the family, and it probably is one of the worst periods of my condition that I can ever remember. I didn't feel, after everything I'd seen and been through, I didn't feel that my condition was even significant on the scale of illness, and I did become quite poorly and quite depressed myself. That was a very, very difficult time, and in the end I did actually go to the clinic - myself - and say to them "I need some help", because I was feeling pretty poorly at the time. So, that was a very traumatic time in my life, obviously followed by a wonderful time - marrying my husband. But it's really where I did realise that, you know, my condition and my health are extremely important, and it opened my eyes to how I'd perhaps been for years previous. And I've made a very big conscious effort to get my health back on track. So, regarding my husband, he's been fantastic. He's always been supportive, but I

(16) guess there's still a little thing in me where I feel "well, I've had this condition so long now, I don't need to rely on anybody else". So, I've perhaps not involved him as much as I should have done, and I know that that, on occasion, has been very frightening for him. He knows how to deal with my hypos, he knows how to give me injections if I need help, but I suppose he doesn't understand enough about my condition, which is frustrating for him, and I guess a bit upsetting for me as well, because I do feel very much like I'm still coping with it on my own. You know, he has come to the clinics with me as often as he can. It's not always been easy because of his full-time work, and I know that he wishes that he could get more involved, you know, and it's something that we hope could happen in the future, where partners can get more involved.

How could he be more involved?

I just feel that maybe, you know, if there was any types of discussion groups at the clinic where we could take our partners or our families along and talk, and perhaps ask the questions that they have or he has. And he does have questions, but I think he feels that he can't always ask. I think he feels that he shouldn't ask and that I have everything under control, and, you know, it doesn't need to be talked about. And I just feel, sometimes, that it would be good to have him there, you know, to listen to what the doctors have to say, and get involved more in the treatment side of things.

What sort of questions does he have?

I think he understands the basis of what happens with low blood sugars, high blood sugars, but I think questions about what is diabetes, where has it come from, you know, what could be the outcome; this type of thing. All the things that I have discussed briefly with him, but I guess I don't know his feelings deep down. It's not something that we talk about too often, as I say, because I just cope with it and I just get on with it. And whether that's a mistake on my own part, you know, not involving him as much as I should, I don't know. It can be hard sometimes.

You say that it's sometimes been frightening for him. Can you remember one of those occasions?

There's been

- (17) several occasions where I might have had a very bad hypo, and Nick, my husband, has had to go and find me something to eat or drink, because I've not been very good about taking something with me or being prepared. He copes very well under pressure, but I have seen the fear and the fright, that, you know, it's not nice to see your partner sitting there shaking and sweating and looking pale. And it doesn't matter how much I say "well, this is what will happen if I have low sugars" - I don't think it ever prepares you for when you see it. And because of my confusion, sometimes, when I have low blood sugars and I can't communicate very well, I feel that it frightens him that he can't talk to me in my normal, logical, clear way, and I think that's what he finds the most frightening.

And what work are you both doing now?

Right, well we actually... I lost my job about three years ago. I was made redundant from the factory that I'd worked at for twelve years, and I was at a bit of a loss. I didn't know what I wanted to do with my life. I knew that, you know, I'd had enough of the factory environment and I'd always wanted to work for myself, so my husband and I decided that we would start our own business. And we've actually gone into the unusual world of stretch limousines, which we hire out to clients for a variety of occasions: weddings and parties, that type of thing. We now own two limos. It was very exciting in the beginning - we've been established for nearly two years now. Very difficult, very, very hard work

- again, little bit hard with my condition. As you can imagine, cleaning two cars on a regular basis seemed to increase my hypos and things like that. But it really was, you know, it was a good thing to do; it's been a positive thing to do. It's given us a turnaround in our lives, and, you know, it's given me a more positive outlook. I've been looking after myself better.

In what way?

Well, as I said, once I lost my father, this is kind of why we decided that we were going to take the plunge and go into this business, which we don't regret. And also it was a real sort of boost to look after myself better. I, about twelve months ago, actually went onto the insulin that I'm on now, and it's... my condition is better, as far as I'm concerned, than it's ever been. I feel a lot healthier, I don't feel so tired all the time; just generally taking better care of myself, so it's really been a positive boost in both aspects.

(18) I remember when I spoke to you on the phone about a year ago, so that would be December 2003, you were about to go onto this new insulin, so can you tell me what that was like?

It was a very worrying time for me. I had ignored my condition for so long, and it had been so long since I'd actually changed my insulins, that I had become a creature of habit. I was told that the best way to go about this insulin change was to actually go to a workshop at the clinic, where they would discuss, you know, the actual new insulin and some breakthroughs in eating the right foods, and that type of thing. I was very frightened. I was very frightened because I still had an old-fashioned way of thinking, and I just wasn't sure I could get used to having to think for myself again, rather than being in the usual routine, and, you know, having to change things. I went to the workshop and found it very informative. I met about ten, twelve different people, who had either been diabetic long-term and some diabetics that had not long been diagnosed. And it did actually turn into quite a discussion group about living with diabetes, which I'm not sure was what it was supposed to be in the first place, but it was a fantastic day. And it just made me realise that all those thoughts that I had, and fears - that I felt I was being unreasonable at the time or the odd one out - there are just so many people feeling the same way that I feel, and that applies to both the long-term diabetics and the newly diagnosed diabetics. And I found that day extremely helpful to me. I actually took my Mum with me as well, because again, she was very set in her ways about the condition, and it opened our eyes a lot. And I came to realise that I needed to let go of the old-fashioned way of thinking if I was to improve my health or my prospects for the future, which I did do. It hasn't been easy. It's been a bit of trial and error for a few months, and I wasn't entirely sure that I was going to suit this new insulin, but I do feel healthier than I have actually felt in many years.

Can you spell out what you mean by your old-fashioned way of thinking and your mother being set in her ways?

Probably because of such an extended period of trying to

- (19) ignore my condition. Things were moving along - there was a lot of new insulins out there. I had so many opportunities to alter my dosages, my insulins, try different treatments, and I deeply regret not keeping up with those developments. So, I still had the old routine. I didn't want to change my insulin - I wanted to stick with what I knew, because I was frightened that if I changed it, there would be some sort of a disruption in my life again. I didn't want it - better the devil you know. And that was why I avoided it for so long, and the same with my Mum. You know, I guess I didn't always tell the truth. I always said that "yes, I'm fine, I feel fine" when, necessarily, I didn't.

You didn't still weigh your food, did you?

I didn't, no. I don't weigh my food. It's again, that's been a little bit difficult. I mean, I do know a lot of things, like pieces of bread and their carbohydrate values, and, you know... But a lot of it still can be guess work, which can be difficult sometimes if I'm going out for a meal and I'm not sure what I'm going to be eating. And I do find that, you know, I have to think quite hard about what I'm doing. But as the years go on, the carbohydrate content of a lot of foods that I knew change as well, and I've just had to learn that I've got to keep up with it. I've got to stop... I have to get out of that old way of thinking and thinking "I know best", "I know this is the way it is", because it doesn't stay the same. And, you know, if I'm going to be at the best health I can be, then I have to learn to go along with the new developments, which is something that's very new to me, but I'm learning slowly.

Have you had any follow-up to that workshop?

I haven't. I've been to the clinic since. My sugars were not good when I started on the insulin, and the last readings were showing that it was actually coming down, which is good. And again... well, unfortunately, due to illness, I couldn't actually make my follow-up meeting with the nurse, but, you know, my condition has improved, and that's very, very good news to me, because I was very worried about it at one point.

- (20) And I'm just very glad that I tried the new insulin - Glargine, and I feel, at this stage, that, you know, it's the most suitable treatment for me. And, you know, I'm just learning that perhaps in the future, if this one sort of isn't any good anymore, then I can move onto the next treatment, which is the part that I'm trying to get myself into with the nurses and the doctors. And, you know, they are very helpful, and...

Have you found or can you remember any changes in the way doctors and nurses have treated you over the years?

Very much so. I never came across so many specialists on the subject before. I remember as a child, sort of five, six years old, I used to have to go to the Infirmary in Worcester, sit and wait for three or four hours at a time to see one doctor, who did specialise in diabetes at the time. And there was never an

occasion I remember without there being twenty or thirty other children sitting there waiting, so it was a very long and boring and traumatic day for me, at that age. But there was never any diabetic nurses, really, or any other doctors. So, now at the clinics, yes, attitudes have changed a lot, and there's people specialising in the subjects, which... it's very reassuring and very informative. It's just a case for people who have been diabetic long-term just trying to accept the help and move along with the times. So, I think the clinic that I go to now, the fact that there are so many different people specialising in so many different subjects to do with diabetes is just ideal, because you know that you're not on your own with any part of it.

Who do you find more useful - the doctors or the nurses?

The nurses; definitely the nurses. I mean, the doctors are obviously so busy, and they have to see each patient every day, and I guess summarise the notes about the way your control's been and that sort of thing. Whereas the nurses are there afterwards to pick up those pieces of information, and try and give you some helpful advice on the best ways that you can change it or to help yourself a bit better. So, I do feel that I prefer to talk to the nurses, because obviously they do have the time to sit and spend with you to go through your concerns, and their concerns as well.

You mentioned that sometimes cleaning the cars might give you more hypos,

(21) but, in general, how does the rest of your new job fit in with your diabetes?

Much better, to be honest, because I do actually work from home, so I can take a lot better control over my levels and my testing, whereas before, when I was in a full-time job, it could be very difficult to get out of my seat at certain points to go and test my sugars or deal with hypos. I feel less restricted now that I work at home, because I have more time to sort of concentrate. If I'm feeling slightly unwell, I can test my sugars on the spot and I can treat it on the spot, so I do find my self-employment a lot easier.

But are you working full-time?

I do work full-time from home, apart from one day a week where I do actually work for a wedding photographer. I find that very enjoyable as well, and again, all of the staff there are extremely understanding of my condition, but they do know many diabetic people, which seems to be something that has increased in the last few years - definitely a more common condition. So, really, everything I do in my working life suits my condition much better.

Can you describe a typical day in your life from the moment you get up?

A typical day in my life: pretty much phone calls, many phone calls, dealing with clients or prospective clients for the limousines, which I really enjoy. I enjoy meeting new people or talking to new people. Car cleaning is a big part of the job, and admin - I've never actually had to think so much. But it's a very varied job and it keeps us active, which is always a good thing, whereas before I was

sitting in a factory eight hours a day and not doing much of anything at all. So, it's very busy lifestyle, a very busy lifestyle, but I think it's a good way to be and we enjoy it.

Would you think of having children?

No, we don't want children. I'm not sure if we'll change our minds in the future. I know many years ago I was actually frightened of having children, because of... the doctors used to tend to say to me, you know, "you have to be so careful" – well, they still do say it obviously, but I think they used to drum it into you a lot more many

(22) years ago – "it can be dangerous for diabetics when they're pregnant", and that type of thing. And I used to be worried that me not wanting children may have been caused by that fear back then, but I realise now that, no, I have too many things I want to do with my life, rather than, you know, at the moment, with children. But it was something that used to frighten me very much. I used to think "well, would they be diabetic?", you know, "how would my condition... how would I cope if I was to be pregnant?". It was all very worrying times.

What keeps you going?

What keeps me going? I have my down days. I have many days where I feel hard done by because of my condition, but I've realised, especially since the death of my father, that it isn't a terminal illness. It's something you can live a very full and healthy life with; it just takes hard work. And I just know that, you know, when I do feel sorry for myself, there's a lot worse out there. And there's so much help available for us nowadays, for diabetics, and it really is just a case of learning to accept the help and to not be frightened of what's coming in the future. And, you know, it keeps me going to know that, you know, it shouldn't affect my life, and, you know, I have a healthy life ahead of me.

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

I feel perhaps I may have had a little bit of a happier childhood. My parents didn't actually believe me when I said quite recently that, you know, it used to affect me. I was quite a sad little girl. I didn't feel that I had many friends, and I couldn't make friends very easily. And I just feel sometimes that if I didn't have the condition, I could have made more of myself, you know, I could have been a happier person, although obviously much of that was brought on by my own thoughts. So, I do believe that perhaps... I enjoy life now, but I believe I could have enjoyed it a little bit more.

What message would you have to somebody newly diagnosed now?

Well, I understand the fears and I understand the traumatic, you know, period in the beginning. It is difficult to deal with - it's a big change in your life. I recently met a young lady who was only just diagnosed, and she was very tearful and very frightened. And I remember her saying to me "I don't know how I'm



going to live with this”, and I can remember saying that so many times, even after many years of having diabetes. And all I said to her was “but you will live with it, and it’s just not as bad as you think, and, you know, there are people there to help”. And I just say to them that I wish I was in the position you are in now with the latest developments, rather than how I was as a child, and that there really wasn’t much help available. It’s nothing to be scared of. It’s a condition that you can easily, quite easily live with and lead a normal life.

(23) What advice would you give to medical staff who are treating diabetes?

As helpful as obviously they are - they’re fantastic people - but from my own point of view, I just feel that there maybe could be more that diabetics could perhaps say and teach to the medical staff about what it’s like to live with the condition. Although their medical knowledge is just amazing, I have felt in the past that it’s not necessarily practical advice that I’ve been given, you know, how to live with my condition. And again, going back to the workshop that I went to recently, I found that all the other people in that room didn’t necessarily want to talk about the insulin. They wanted to talk about the impact that this disease, as it were, has had on their lives, and none of us seemed to have ever have had the opportunity to talk about it in any detail - about how it’s affected us, about how we feel now. And we just agreed that it would be wonderful if there could be some sort of a discussion group where people can go and talk, and just to help them realise that they’re not the only ones feeling what they feel. And from my own personal point of view, the biggest or the hardest part of my condition to handle was the psychological side of it: how I felt, how lonely I felt, how frightened I felt. And I’ve always thought that that was just me, and recently I’ve discovered that every diabetic feels the same, and it’s a lot to deal with. As well as trying to look after yourself medically, it’s a lot to deal with, and it’s very hard to deal with on your own. So, I would like to see, as I say, a discussion group or a workshop where people can go and talk about how they feel, because I do feel that that would be a huge benefit to the condition.

So, you’re talking about just saying what you feel rather than responding to questions?

Well, it was... I just think, yes, to say how we feel, how we have felt in the past, but to be able to actually say to the doctors and nurses “well, this is the advice you have given us, but this is how it’s actually worked in my life”. And I think that would be important for them too, because it can’t be easy, in the medical profession, to be able to give practical and healthy

(24) advice to diabetic patients if they don’t suffer from the condition. And I just feel that it would be a very good way to swap that information backwards and forwards between each other, and perhaps enable them to give, as I say, more practical advice on living with the condition. The people that I met seemed to be so frustrated that they had all this to say, and not all of it good, about, you know, how they’ve been treated in the past and that type of thing, and I just... it seemed to be a really, really

constructive hour that we spent, although we should have been talking about insulin. And the nurses seemed to find it very informative too, where we told them things about symptoms that they hadn't actually heard of before - symptoms with hypos, you know, low blood sugars. I spoke up in the group, and I was absolutely shocked that five other people actually agreed with me, and following on from that, the nurses were actually stunned because they'd never heard of that symptom before.

What was the symptom?

It was... well, it was the symptom of low sugar levels, where I had experienced in the last two or three years - whereas before I knew exactly when my sugars were dropping, and my symptoms were shakes and sweating - cold sweats. I've suffered that all my life, or all my diabetic life - and in the last two years I am now suffering the symptoms of high blood sugar levels when my sugars are actually low. And I've made a lot of mistakes with my treatment with that, you know, by not testing first. And when I brought this subject up, I thought I was sort of gone a bit crazy, and five other people - long-term diabetics - agreed that their symptoms had altered the same, and the nurses had never heard of that before. Perhaps we hadn't thought about it, you know, in a meeting with the nurse, or perhaps I'd just jogged people's memories.

So, what are these symptoms of high blood sugars that you're getting when in fact your blood sugars are low?

With me, personally, high blood sugars has always been extreme thirst, very dry mouth, dizziness, and sickness or a feeling of sickness, and there was always a distinct difference between that feeling and low blood sugar levels. But, as I say, in the last two years they seemed to have swapped places, which has been very confusing to me, and I've had to be a lot more vigilant on my testing, whereas before I'd just think "oh right, couple of units of insulin, bring my sugars down", you know. Obviously, and from speaking to these other people, obviously, perhaps in long-term diabetes, your symptoms do change, and I don't think the patients have been necessarily good at telling the doctors that they're suffering these changes. And I just feel that that would be sort of a very good way to speak to one another, and help them in their research too.

(25) Do you think you would have benefited from meeting other children with diabetes when you were younger?

Well, I did have one opportunity to meet other diabetic children; I was about eight years old. I went on something called a diabetic camp to Wales, and I met about ten or fifteen other children with, obviously, diabetes. It was a two week holiday. All of us, I recall, found it very traumatic for the first week. We didn't actually have the most understanding nurses there, although they were very good. And we had to, as well as having fun - a bit of an adventure holiday, we also had to learn about using new injection sites and those types of things, so it was quite a painful experience in more ways than one. I can distinctly remember crying with other children there, saying "we want to go home". But at the end

of it, we did realise the whole point to the holiday. And it was good fun, and I did meet a lot of children with the same condition, and some were even worse, you know, not as well-controlled as I was at the time. And you did feel a little bit segregated at first - you know, sort of fifteen diabetics in one place, but it was good and it taught us a lot.

Do you know who organised it?

I'm very unsure. I know... I remember little about how my Mum and Dad got me involved - I don't know whether it was through the hospital or through the advice of the doctors. There wasn't a specific name for the people, I don't think. But I think that the whole idea was to get children used to being away from their families and still coping with their condition, so it was a very informative sort of holiday, and it was very good for us, and it kind of pushed us, at a very young age, into learning about coping without our parents.