

25. Mary

(1) Tell me about your background.

I was born in July 1954 in a small village in Cheshire. I am the youngest of three children, so I was the one that was spoilt, I suppose. My father was a baker and my mother was a factory worker. We had a very nice council house in Cheshire, actually. And my grandfather, who I never knew, was diagnosed as having diabetes - I would imagine it was around the time that insulin was discovered, because apparently he used to have insulin transported on the train in the mid 1920s. I know I had an uncle who had diabetes, who I do remember, who unfortunately had cataracts and had to have a leg amputated. So, I know there was a family tendency towards diabetes. My mother had gestational diabetes with me, but I didn't find this out until I was diagnosed. About myself, really, I suppose I was a sp... I don't think I was spoilt, but my siblings reckon I was. I was always classed as a sort of a quite a sickly child: I had a lot of gastric upsets. It would be me that did the projectile vomiting, so they thought I was marred. As a small child I wore glasses, and when I was ten I didn't have to wear them anymore: my sight had corrected itself. And then, when I was about twelve, I did notice my eyesight was not as it should be, but I was not going to admit that there was anything wrong with them because I didn't want to wear glasses. And I would test myself - on the way to the bus stop to go to school I would test myself to see if I could see the pub sign and how clearly I could see it. Sometimes I could see it; sometimes it was a total blur. Same time, I got incredibly thirsty and about Octo... well, it was October of 1967, just before half term, I actually felt so ill I couldn't go to school.

(2) My father, I think, had an idea that I might have diabetes, because of his family history. In fact, before I went to the doctor's, I'd overheard my parents talking about, you know, whether I possibly had diabetes, and I asked my father, and he said "well, really, I don't know". And I didn't see... my father was a very sort of brave, tough, big chap, and so wasn't, at that point, wasn't that easy to show his emotions, and I knew from the way he said "I don't know" that things weren't looking that good. We didn't have a car, so we had to get a friend of my father's to take us to the doctor. I remember - even though it's actually thirty seven years, two weeks and five days ago - I can actually remember very well that week. My father took me to the doctor. We had a family doctor who'd been in the village for years, as had his father, who was surprised that we hadn't had a urine sample, was very dismissive, and said "well", you know, "come back on Monday with a urine sample. I can't tell you now - I'm going away for the weekend". That was on the Friday. By the Saturday, I was... I couldn't actually get out of bed, I was that tired and felt so ill. I got up at night to go to the loo, which is opposite my bedroom in a separate loo, couldn't find my way out of a very small room - I just couldn't - so I was banging on the door. And my parents got up as well, and I think were so concerned, phoned another doctor, who came, who gave my parents a

really hard time about why hadn't I been to the doctor beforehand. And when they'd been told that, in fact, I had been, everything went sort of very quiet. And then, apparently, I was then admitted to a local hospital, and came to about twenty four hours later, in hospital, surrounded by my relatives, who apparently thought I was going to die. And I still, really, didn't know what was going on, having injections all over the place. And I remember very distinctly, the sister, on the children's ward that I was on, gave my parents a hard time. She was under the impression that my parents knew I had diabetes and had let me get into such a state where I was in a coma. I was not very happy about this; mind you, I was only just about thirteen at the time. But I remember being in the hospital for a couple of weeks, being told just purely by the by, you know, when I asked when I was going to stop having these injections, that I never would stop having these injections - which is a great way to tell anybody. I had to practice on an orange, and then my mother had to

- (3) practice giving me my insulin, which was a total nightmare. I think the nicest person on the ward was the - which would now be termed as a - healthcare assistant; she was the most sympathetic. I had lots of visits from friends. Even the milkman came to see me. I think he'd actually felt guilty about me having diabetes, because for a short time I'd accompanied him on his milk round, helping him out, and because I was so thirsty, I used to gulp down the orange juice - bottles at a time - which, obviously not realising it wasn't make me feeling any better. But I think he felt quite guilty, because everybody knew a bit about diabetes, but I think everybody thought it was something that older people got and that younger people didn't actually get, so everybody felt terribly guilty. It was Bonfire Night when I was in hospital as well. I remember being allowed to have one treacle toffee - and that was it, apparently, for the rest of my life; I could never have anything sweet ever again in my whole life. I had to go and see someone in the hospital about my eyes, who I'd seen as a child - consultant eye specialist who I'd seen as a child when I wore specs, so that was a bit scary. But he was actually, for once he was actually very pleasant, and said that, once my diabetes was under control, my eyesight would return virtually to normal, which it did after a while. So, after that, I was discharged, and I was off school for about six weeks. I remember the truant officer came round. My parents had been in touch with the secondary school in the local town that I went to, but they felt the need to send a truant officer around to see us; so that was all explained. I went back to school in November, so I'd missed a couple of months of school, and it was actually quite difficult to catch up with everything.

I'll just interrupt before we move on to school. Going back to your period in hospital, can you remember exactly what you were told about diet?

Nothing. I wasn't told anything at all about diet. My parents were advised to get a book by - I think it was - Lawrence, I think the guy was called, and it was

a Line diet. We had no help at all about diets, it was just that I could have so many black lines, so many red lines, and we had to work it out for ourselves. My mother was told how many black and red lines I could have, but that's the only help we had. We had no booklets, we had no advice. I'm not entirely sure if we actually saw a dietician, but I had no help at all. In fact, every time we went to the hospital, we saw the consultant, but we had no advice on anything at all. It was a case of find out yourself.

What about monitoring your blood sugars?

Didn't monitor blood sugars. At the time, you had to do urine specimens, which, as I remember, I hated it. You had to put, I think it was five drops of urine to ten drops of water and then drop this tablet in, and it would go... it was usually blue, I think, if there was no sugar, and then it would go to various stages of green. I used to hate it; hated doing it. You know, you had to pee into this container, set it all out. It was awful, I hated it. And, you know, as time went on, my mother would always be very keen to sort of... she would actually want to please the doctors, so if I hadn't actually done one, she would put that it was blue. And I knew it wasn't, I knew there was, you know, sugar in it; I mean, you know, a bit pointless to me.

(4) What was it like, then, when you returned to school?

Well, I know for a few years I was the only person with diabetes in the all-girls secondary school that I went to. My mother was always very particular that I would have the right amount of food at the right time, but having said that, she's like that about everything; she took it to an extreme. She would make my breakfast. At the time, I was supposed to have scrambled egg or bacon and egg, which - she went off to work - so she would leave it on a pan of water, and I had to eat it. So, it could be about half an hour old by the time I got to eat it, but I had to eat it. And I had to take a mid-morning snack at break, and because we had no dietary advice, I couldn't actually work out from school dinners - well, I was told I couldn't have school dinners, so I had to take a sandwich, and I found that quite difficult. And then I had to have extra food if I did PE. And I was always very good at PE, so I hated having the extra food to have it, because it just sort of singled me out even more. And at school, we had this system where, as you got older, you could be the head of the table, which, you know, we all look forward to being the table leader or whatever. But, of course, I had to sit on a separate table because I was eating something different to everybody else. As time went on - and it must have been only quite a short time, because I left school when I was sixteen - various people were eating different foods, and you were allowed to bring your own. If you had a dietary need, you could bring your own sandwiches in, so... Actually there was... one younger girl was diagnosed as having diabetes, so this table was organised - it was for people who had dietary needs - and I became table leader of it. But this table was actually set aside from the rest of the school. I mean, looking back on it, it's absolutely awful that we were actually, literally, you know, pushed to one side, and weren't... I think they thought if we weren't actually in the dining room,

it would be better for us, because we weren't eating what everybody else was. But, you know, how isolating; how awful to do that. It was, you know, it was quite bizarre, but fortunately I managed to carry on doing gymnastics, and it didn't affect that at all, and I was quite successful at that. And then I... well, I left school at sixteen and went to a Further Ed. college, and then I changed. I went to another Further Ed. college, and I actually decided to go into nursing for a while. I think, probably, about fifteen or sixteen... I found it very difficult at fifteen and sixteen, because I was starting to go out and go to discos and so on, and I would have to take... I used to have to have a snack of crackers and milk about half past eight, so my mother would insist I took it out with me. So, half way through the evening, or just when I got wherever I was going, I'd have to go off to the loo and have this milk out of a Tupperware container and these crackers and cheese. I mean, god! And so, I think about that time, I, you know, decided... well, I don't think I ever decided, but I just - I don't even know you could call it rebelling - but I knew I wasn't going to do everything I was supposed to do any more; I just wasn't.

- (5) I mean, I think probably part of it was I didn't start my periods until I was fifteen, but weirdly enough, I'd actually been - well, I think it's weird now - I'd been told, or my mother had been told, that when I started my periods that the diabetes may go away or it might improve, and so on and so forth. So, of course, it was announced to my father that I'd started my periods and that they would have to tell the hospital and so on, and, of course, at that age, I was highly embarrassed. I didn't want... I was pleased that I'd started my periods, because I was quite late in starting my periods, but I didn't want everybody else to know. And it actually made no difference whatsoever; not that I could see. So, I think - I don't know whether it was a turning point - but I think after that - and I was actually obviously becoming more independent and going my own way - I went to FE and then I did some nurse training - so I knew... you know, I'd started to have extra things to eat, not necessarily sweet things, but, you know, I'd have an extra bowl of cornflakes here or I'd... My sister and I, what used to happen, we used to come in before my mother got home from work. We used to make ourselves something to eat, and I knew that I shouldn't be actually eating any different, so my sister came up with the idea that if I had toast, I could just chew it and not swallow it! - and that would be fine. So, that's what we did. I don't think I actually did it for that long, because it wasn't - you can imagine chewing some toast and then spitting it out and trying not to put it somewhere where your mother couldn't find it. So...

So, thinking that your diabetes might go if you had a period, and that it would be all right to chew toast and spit it out, shows a fair degree of ignorance about diabetes.

Well, yeah, completely. I mean, my father knew some about diabetes, but, of course, he'd only had experience with older people, his relatives, with diabetes.

And, as I said, before we were given this book or advised to get this book, which was quite an academic book - and I can remember looking at it on the bookcase and looking at what I could eat with this bloody black and red Line diet - but it was just sat there sort of not necessarily pride of place, but I don't think it was ever looked at. My parents were never actually given, as far as I know, any advice about it. And when I visited my GP, he was totally antagonistic; well, I thought he was. When I was at school, I wanted to go on a cruise with the school. And I'm not sure - I think my urine samples mustn't have been terribly good - because my GP - and I had to get my doctor's... because I had diabetes I had to get my doctor's permission to go - and my GP's saying to me "well, I don't think I'm going to sign it for you. You know, you're obviously not behaving yourself. I don't think I'm going to sign it for you". So, I actually asked the consultant next time I saw him, and he said "I don't see that's a problem at all". So, the consultant, at the time, was actually quite a paternal chap, but I actually quite like him. I think my mother was actually scared to death of him, but I saw him quite a lot. As I say, he was quite paternal, but he was actually okay; he was quite a gentle chap. But I do remember sort of going with my mother to the hospital and thinking "there's absolutely no point in this. She's going to sort of waffle on, talk about whatever, and she doesn't actually know what she's talking about. I don't want her to come with me any more". So, we had quite a battle to do that when I was about sort of fifteen and sixteen. And my mother was a person who - to describe a bit how she was, she would actually flare up, at times, with each member of the family, and my parents always argued. And I do actually, you know, remember - not so much about... well, they'd argue about anything actually - but I do remember she would order this massive amount of fruit every week, which was for me. Everybody else had cream cakes on Saturday, but I'd be the one that'd have stewed fruit and cream, which really didn't replace it at all. But we used to have grapes delivered and she'd have a box delivered, and always had to be the same things, you know, you had to have a pound of apples, two pounds of grapes and so on. And she must have looked at the book, because

- (6) I remember her arguing with... or hearing my father and her arguing about it, and my mother saying how expensive it was to buy the special foods that I needed, and so on and so forth. My father couldn't come up with anything, but I do remember them arguing how that, you know, basically having to have lean meat, which you were then advised to have lean meat, and fruit and this that and the other, and just hearing them arguing about it.

Were there any special diabetic foods available?

Yes, I remember distinctly - they were absolutely foul. One Christmas I got about - it may have been a Christmas, you know, not long after I was diagnosed or the year after I was diagnosed - and everybody decided to buy me diabetic chocolates, which to me were just like laxative chocolates. And I think I actually gave them away to the local hospital; they were foul. There was absolutely

nothing. There was some awful diabetic squash, which is absolutely no point in having it at all; it was disgusting, you know. And I think my mother did try. She did buy the occasional box of chocolates, but there was no point; there was nothing. It's not like it is today. There was no low-fat, there was no low-calorie, there was no reduced-sugar. It was awful; you couldn't have anything. I mean, in some ways I don't have... you know, I've not missed fizzy drinks - I don't drink fizzy drinks. So, I think people who are diagnosed in the last, say, ten years, they're quite fortunate, or not, that they can have Diet Coke whatever. I mean, I don't like it, so maybe I'm the fortunate one - I don't like fizzy drinks.

So what did you do if you went out to a pub or a club in your teens?

I drank beer. I didn't drink beer, actually, until I was about eighteen, but by that time I wasn't particularly bothered about anything very much. I left home shortly after I was eighteen, and what I did - I had my insulin twice a day, and that was it. The rest of the time, I just carried on as everybody else was doing, and didn't pay any attention at all. I didn't take my urine testing equipment, because you still had to test your urine at that point, and I wouldn't take that. I mean, I may have taken it when I left home, but I certainly didn't use it. So, the only way of finding out what my blood sugar was, was if I had a hospital appointment, which I did keep, was when they did a blood test then, and it used to be very high, and I would just carry on.

Did you notice any difference in your health between the earlier years, when you were very strict about your diet, and the later teens when you weren't?

I got fatter, actually. I mean, I was very thin to start off with, before I was diagnosed, and I did put on quite a lot of weight in my early teens. Maybe I would have done anyway, but I did put on weight, but I didn't notice whether I was particularly healthy or unhealthy. I don't think so. In fact, I mean, I never have been. I've never been particularly...

- (7) since before I was diagnosed, I've never been particularly unhealthy. I'll get a cold, but it's no worse, you know, than anybody else's, I don't think.

Did having diabetes affect your choice of career at all?

Yeah. I distinctly remember being told at school I couldn't work with heights, so I couldn't become a steeplejack! And I do remember, I did actually want to be a journalist, and I don't know... well, as regards that, I mean... Actually, thinking about it, I did actually - my father was in the Navy in the Second World War - and for some reason I decided I wanted to join the Wrens. So, we went to a careers evening, when I was still at school, and there was a Wren there, and I was just told I couldn't join. I had diabetes - no chance. And I did feel, actually... I didn't feel resentful, but I remember being quite upset, and maybe I did resent it later on. I mean, I'm not sure whether... I suppose I did think "why me?", but as things have happened in later life, I suppose, now, I mean, you know, "why not?".

How did boyfriends react to your having diabetes?

Well, the first sort of - well, I don't know if... well, he wasn't a serious boyfriend - he knew me, anyway, we were the same age, and it didn't come into the equation at all. The first sort of serious boyfriend I had, I don't think it caused a problem at all. I mean, I used to tell most people I had diabetes. It didn't affect us at all - not that I can remember, because I certainly didn't have hypos then. I just, as I say, I just carried on. I just had my insulin twice a day, and that was as far as I was willing to go, and sort of kept to a diet, but not really.

(8) What did you do after you left home when you were eighteen?

First of all I did some nurse training. It wasn't general nursing; it was what's termed "nursing the mentally handicapped". But then I met another chap, and we started to move round the country - this was when I was about nineteen. And I remember signing on, and the chap sitting there at the desk, and - I don't know, he must have had to fill in this form about medical something or others - and telling him I had diabetes. And he was asking me if I wanted to be-class myself as disabled, because the employers had to employ a certain amount of disabled people. And he was asking it in such a way, where he obviously thought it was a terribly good idea. I mean, I was about nineteen at the time - I certainly didn't feel disabled. I mean, I felt a bit, you know, I knew there were certain things that I had to do, and as regards doing anything... 'cause when I'd been nursing, I never had to do nights, but I'd often wondered how it would work if I had to work nights. But, you know, apart from that... So, I politely refused to be classed as disabled. Might have been quite useful, but I decided, at the time, I wouldn't do it. And I did move round the country quite a lot. We had a caravan, and we moved to Brighton, we moved to Wales; we moved all over the place, actually. And there, again, I would actually always make sure that I had a doctor, and I would attend diabetes clinics - they weren't termed diabetes clinics - but I used to turn up and have a blood test. And I actually thought that was the way of doing things, and that if I had a blood test, for some reason, that would be all right, and they'd just fiddle around with my insulin. But they never did, because... And I think they may have actually, or maybe it was sort of later on, that they may have wanted me to sort of adjust it, but I couldn't really adjust it, because I didn't do any testing, and they still weren't having blood tests. So, I think the amount was probably fixed by the hospital, which is a bit crackers really, 'cause, you know, from one week to the next, you know, your dose can change, but that's how it was then. You were still doing urine samples, which I was not ever going to do again in my whole life. It was so repulsive, I just wasn't going to do it; I mean it was crackers.

(9) So, we're in the mid 1970s now. What happened next?

Well, in the mid seventies, for some obscure reason, my partner and I decided to get married, for various reasons that have escaped me now. And about the same time, the house that we were living in, there was a podiatrist in there, and what I thought I'd do, I thought I would go back to nursing, and I was going to go back to Brighton and become a sick children's nurse and a general nurse. And they accepted me for the general training, but, because I had diabetes, they decided it

would be too much work for me to do and I couldn't do both, so they'd have me for general nursing. But, in the meantime, I'd met this chap who was a podiatrist - they were called chiropodists then - and I decided I would go and have a look what he did, not realising quite how much it involved diabetes, and I decided I would train to be a podiatrist. So, that same year, we moved to Manchester and I started at college to become a podiatrist. I was still not doing anything to control my diabetes, and, apart from urine tests, it was never suggested that I should. And I actually was attending Manchester Royal Infirmary, which was a great experience, I have to say. I went in one day and - so by this time I would probably be in my early twenties - and this guy, I think he must have... I mean, by this point, I didn't see any point in lying what I was doing and what I wasn't doing; I didn't see the point. I mean, I'd figured out, from the little I knew, there was no point in giving false results or saying you'd done them if you hadn't. And this chap, this doctor, said "right, well you're obviously not looking after yourself, you know. If you're not careful, you will go blind and your feet will drop off". And I'd said "no, they won't", and he said "yes, they will", and I said "no, they won't, because I will commit suicide" in which I then got up and walked out, and said to the nurse "I do not want to see that chap ever again". The next time I went to the hospital, there was a consultant. And I did actually complain about this chap, and apparently it was because he had seen some people who had diabetes and the diabetes had got very complicated and so on and so forth, and so that's why he took his temper out on me, which actually was no excuse whatsoever. This consultant was actually a lot better, and told me of cases where this old guy, who presumably had maturity onset diabetes but had to go onto insulin, who they discovered that he used to carry the needle for - 'cause you'd had to use metal syringes then - he used to carry it around in his lapel. And they persuaded him not to carry this needle around in his lapel, and to

- (10) make everything sure everything's clean - because then, of course, you still had to boil your syringes up and keep it in surgical spirit. And this old guy, as I say, carried it round in his lapel, and when they persuaded him to be a lot cleaner about it, that's when he started getting problems. So, this consultant, for the first time, actually said "well, actually, you know, you might know more about your condition than we do. We can advise you, but, you know, it's you that's got to deal with it".

That sounds quite like a turning point, so you couldn't pin that down to a year could you?

I would say that was probably, roughly... maybe the late seventies, I would think, by this time. But, of course, you know, Manchester's a big teaching hospital, so, you know, maybe that's where the difference was. I was learning about podiatry and was treating people who had diabetes, but even though I'd had relatives who'd had amputations, I never actually... People would very sort of gently ask me if it bothered me, and I have to say it never did. I'd actually... looking back on it, I suppose I thought I was different to the elderly people that



came in, and I never actually put myself in their position. But I never have... not until I've got older have I actually sort of compared myself to any patient that I've seen anywhere else. I don't know why; whether it was a sort of a safety mechanism or not, I don't know. I mean, this is what I'd sort of... it occurred to me, oh, quite a while ago, I don't know that... the personality that I have now - I was very shy as a teenager, as a small child - but because of having had diabetes and having to eat at certain times, I'd had to sort of... if I was out anywhere, especially when I was moving around a lot, anybody's house, I'd have to say "well, you know, I need to eat now. Could you give me something to eat?", which is actually quite, you know, it's quite difficult to do. But all this leads me to say, I'm not sure how... what sort of person would I have been had I not had diabetes? I don't know how much it has shaped my personality. I don't know why anybody doesn't actually do any research into that actually, because someone who's had it for as long as I have, it must have had an effect on the personality, you know. I mean, I think some people actually go completely over the top with it.

Do you think that you needed any psychological help or counselling with your diabetes at any stage?

Absolutely, right from the word go. I mean, as I said before, I never got any; we never got any help. Yes. Ideally, what I would have preferred, I think, looking back on it, is a younger

- (11) person dealing with me when I was first diagnosed, but have had an opportunity to go and talk to somebody. Now we have diabetes specialist nurse, although I don't see mine very often - I'm not entirely sure who mine is - but there was nothing; there was no support, you couldn't talk to anybody. And literally for years I have been telling various hospitals that they should have a psychologist, or just someone that you can talk to about having diabetes, you know, just so you can go and say "I've had enough of this", or whatever problems you've got, just that you can actually walk in. I do know that... I've heard along the way that adolescent clinics don't work, and to be honest, I'm not surprised they don't work. Having said that it would be a good idea to have someone to talk to, I'm not quite sure how you do it, but they're actually missing the point. They do these evenings for people with diabetes. It's not the right approach. I don't quite know what is, but I know that isn't, and they don't have very high attendance; I know they don't have very high attendance at the young diabetics' clinic. You know, maybe they should ask me to help - I don't know, but I know they always get it wrong, and looking at it from the outside, I know why they did get it wrong. One of the reasons I think that adolescent clinics - meetings - don't work at that age - I mean, I don't know what age you would say adolescence was, can be anything from like thirteen up to nineteen, your early twenties, I think - but they don't work because all the staff try to be terribly hip, and, you know, okay about diabetes, but you just want to say "oh well, you know, you're talking a load

of bullshit. You've no idea. You've no idea what it's like to have diabetes - forget it, so just don't try and be terribly hip about it". Don't know how you get over that. I remember one doctor saying to me - and I wasn't an adolescent, it's in Oxfordshire - "well, you know, I've... ", you know, and I said to him "you've never had a hypo", and he said "yes, I have", and I said "oh, come on, how come you...?", he said "well, I accidentally overdosed myself with insulin". I mean, please, how did he overdose himself with insulin? He gave him some insulin to see what it would be like to have a hypo. Doesn't work, doesn't work.

(12) When did you move to Oxfordshire?

Well, my marriage split... we split up in '81 or '82, so I moved to Oxford in about '83, I think, and started to attend a diabetic clinic here, which, for some reason - I'm not quite sure what - I actually did notice that things were slightly different. They actually were listening to me a bit more, I think, and they were quite concerned that I would get my blood sugar more under control. And it was then decided, or I think it was MediSense had started having blood testing machines, and I was advised to buy my own, which I did, which was quite revolutionary, really, because it used to take still quite a while, and I didn't like pricking my finger to do it, but I started to test my blood sugars more. And I still didn't want to be that involved in having diabetes. As I said before, I was quite happy to do it twice a day, and testing your blood sugar meant you had to take it more on board. You had to sort of pay more attention to what you were doing, because then you were faced with - you'd got a high blood sugar or a low blood sugar and so on. But I think I must have been more careful what I was eating, and I think it was probably more that I didn't want to put on any more weight, and that had something to do with it, not the diabetes. But I realised, if I stuck more to my diet, I possibly could lose weight. But I think the significant thing about then was, because I was trying to get my diabetes more under control, I actually realised that physically I could feel the same in the morning as I did in the afternoon, whereas before I would generally go hyper towards the end of the day, so I'd feel... it's actually a particular feeling, that, unless you have diabetes, you wouldn't know what it's like, but it's actually very strange and a very uncomfortable feeling if your blood sugar's high. But I found that if I was more careful what I ate and what I did, I could actually remain feeling the same all day, which, surprisingly enough, was a total revelation to me. It was great - you know, physically and mentally, I felt the same all day - well, not mentally necessarily - but physically I could feel the same all day. So, I got my diabetes more under control then. I would generally only do... I would think "oh god, I've got to go to the diabetes centre, I'd better do some", but I was never fussed. I mean, if they were up, they were up. I mean, I just decided that, you know, those are my blood sugars. I'd do about two weeks worth, and they would say "well, you know, you need to do some more". And,

(13) you know, I remember one chap, you know, telling me that I was very naughty and so on, so, you know, I can see my face at the time thinking

“oh god”, you know, “I’m very naughty”. I’m sort of in my early twenties - “please”, you know, “whatever”. But it was actually... things - I don’t know if it was Oxfordshire, I don’t know what it was, or whether it was the people around at the time - but I remember them saying to me - and I think it’s when I probably started to use plastic syringes, although I had tried using plastic syringes when I was in Manchester and couldn’t use them at all. It was agony - I don’t know why. My technique was probably up the shoot, but nobody particularly helped me with that either - but anyway, in Oxfordshire, the doctor had said, or some nurse had said “well, you don’t have to swab your legs any more”, because you always had to swab your legs with a piece of cotton wool and surgical spirit or a mediswab. I mean, I’d stopped doing that anyway - it made the top of your legs go like a pie crust. You know “you don’t have to do that anymore”, and I said “well, I haven’t been doing it for about ten years anyway. I know my legs are clean, you know, I’ve stopped it”. And they were sort of a bit surprised - “oh right, well, fine, absolutely, and, you know, carry on, do whatever”, so I thought “well, I’m going to anyway”. So, I don’t know if you would say I was going to be more responsible about diabetes, I’m not sure. When I moved to Oxford and I met my present partner, who I told him I had diabetes, he knew actually very little about diabetes as well. But strangely enough - I mean, I didn’t find this out until we’d been going out for a couple of months - his sister, her partner had diabetes and he had been diagnosed when he was five. I mean, to me - you know, we didn’t actually discuss before we decided to start seeing each other what our history was of diabetes - but I found it quite bizarre that, you know, that his brother-in-law would have diabetes from a child as well. But we never talked about it. In fact, I didn’t actually get to know him that well - he unfortunately died of a brain tumour, nothing to do with his diabetes. But, you know, thinking about it now, it’s quite bizarre. So, we didn’t discuss diabetes between us, only sort of briefly about, you know, how rubbish the doctors were. But it was about that time that I did sort of pay more attention to it, but the awful thing about paying more attention to it was, the better controlled you are, the more hypos you have. So, where have you go to go with that? I mean, you know, who wants to be in danger of having hypos? I realised that with having high blood sugars, because of the job that I do, I realised

- (14) having a high blood sugar can lead to neurovascular problems, especially with feet. But who wants to go hypo or be in danger of going hypo? And I’ve said this to doctors, repeatedly: “well, there’s nothing going for being well-controlled is there, you know, not immediately?”, and they always say “well, long-term - yes”, and I can see that, but short-term, if you’ve got to think “well, I’m in danger of going hypo, you know, I’ve got to do this”, it invades your life even more. There again, I don’t know what’s round that, but, you know. I actually learnt to drive when I was in Manchester, but now, if I’m going any distance, I have to make sure, you know, “how

long is it going to take - do I need to eat?" And I have gone hypo when I was driving, and it was a two lane road in Ireland that suddenly turned into a six lane road in Ireland, and my partner said "I think you ought to pull over", which I did eventually. Actually, talking about driving, I learnt to drive when I was in Manchester, and I think the law changed just before I took my driving test. I suddenly couldn't be insured on my then partner's insurance because I had diabetes. I had been before that, but I hadn't really driven. But they wouldn't give me a provisional licence, they wouldn't insure me as a provisional driver, so how the hell you actually learn to drive, I wasn't entirely sure. I remember going into insurance office, and they wanted - the law must have changed - because they went through this whole big thing about how my diabetes was controlled, what happened here and what happened there, and all the information about it. They didn't know anything about it, but I think, you know, that's what they had to ask, and I remember saying "yes, and I've got a mole on my back as well". And anyway, I actually had to take a disabled driving test. I took it once and failed - nothing to do with the diabetes, it was my reversing. I took it again, and had a different driving instructor, who was brilliant, and passed it. And I said "well, what's the difference between a disabled test and, you know, non?", and he said "well, quite simply, you know, everyone else takes it on the hour. If you have to take a disabled test, you take it on a half hour". After I passed my test, I thought "right, I've taken a disabled test, I'm going to have a disabled ticket - sticker", so I marched off to the council offices, where I was told I would at least have to lose a leg if I was going to get a disabled parking permit! So, I said "well, I'll just hang on for that, thank you very much. I'll wait another forty years for that".

(15) Tell me now about your pregnancies.

Well, I'd been in Oxford and with my partner for a couple of years, and I had started to think about pregnancy and wonder if I was actually fertile, because the time I'd been with my previous partner, I'd not used any contraceptive at all for about eight years. So, I'd presumed my fertility rate, for whatever reason - probably the diabetes - was actually quite low, and I'd thought about it, but hadn't actually decided whether I wanted to have a child or not. And my partner and I, I think we'd probably talked about it, but I went to see a chap called Gillmer in Oxfordshire when I moved here, and I said "I just want to find out if I'm fertile or not". But, in the meantime, I actually did get pregnant. My diabetes - I wasn't actually testing it that well, but I became pregnant and we started living together, and the early stages were absolutely fine. Later on in the pregnancy, I would go hypo quite easily, and I think it was at this point my partner, I think - well, had to understand more about diabetes, and, well, obviously he had to recognise a hypo. I remember one particularly awful hypo that I'd had while I was pregnant, where it was like having a fit. My muscles clenched and unclenched, and I was actually not conscious, but semi-conscious. And I remember, actually - it was very difficult, as I say, because my muscles

were going “achhmm” - clamping - and I was trying to make out on the wall, I was trying to draw a nine on the wall to get him to ring 999, because I knew that how I felt that I was just... this was just awful, which he eventually did. And after that, he got to understand a little bit more about diabetes. And he’d never had any experience of it, as I say, from his brother-in-law, but he did begin to understand a bit more about diabetes and how fragile things were. I did continue with my pregnancy, but towards the end, I think, by the end of my pregnancy, the blood sugars that I was having taken at the hospital were a lot higher than the readings that I was getting. And I think there, again, it was my technique and I wasn’t putting enough blood on it. And I had to be hospitalised for two or three weeks - this is in 1985 when my first child was born. And it was decided, at some point, that because my blood sugars were going up and down so erratically, for whatever reason - I mean, one of the reasons was I was just sat around in the hospital for about two weeks -

- (16) but it was decided that they would induce labour, which they did, which wasn’t successful. And then, I think that the baby must have shown signs of distress, so they decided to do an emergency caesarean, which meant that I couldn’t stay conscious, obviously, for an emergency caesarean. So, I was taken to theatre, and what I remember, the obstetrician had decided that I would need an insulin drip up while I had my first child and the medics in there didn’t think that was a good idea, so I was anaesthetised hearing medics arguing about - one was saying “well, Mr Gillmer says...”, the other one was saying “well, we don’t agree with it”. So, I was anaesthetised, you know, to that. I came to several hours later to be told that my son was very ill; they weren’t quite sure what it was. And I managed to go and see him, and he obviously was very, very unwell, and did, in fact, die shortly afterwards. And it turned out it was transposition of the great vessels, and to this day I don’t know if it was diabetes that caused it or not. I did know that your diabetes... it’s far better if your diabetes is very well-controlled during pregnancy, and I did ask whether it was the diabetes and nobody’s actually said whether it was. They think it was probably just something that happened, but I knew my diabetes hadn’t been well controlled, so... And I’m not entirely sure whether I want to know now. I can’t do anything about it, but I don’t think I want to know.

What happened, then, after your son had died?

Well, obviously, you know, it was a very painful, very difficult, and I have to say that I did have a lot of support from the hospital - they were excellent; very supportive indeed. And I was actually told at my postnatal, if it happened again that I’d have to terminate the pregnancy, because at that stage - we’re talking about 1985 - they didn’t actually do any scanning of babies in utero, so they didn’t know... they couldn’t tell until babies were born if they had a fault. But I was told if it happened again that I would have to have a termination. We actually - it took quite a while - and then we decided that yes, we did want another child, but it was actually three years later. And I still hadn’t used any

contraception between

(17) that, so I went back to the same obstetrician that I'd seen, who... I had to do the usual things when it's anything to do with infertility - but he was a specialist in diabetes - taking temperatures and so on. And I took a fertility drug for a couple of months, but meanwhile making sure my diabetes was very well-controlled, because although they'd not said, I knew that it was very important to keep your diabetes under control in pregnancy, and certainly in the first trimester. So, I became pregnant, and I still had hypos, but I was very closely observed - after what had happened in the first pregnancy, I was very closely observed and supported. And I decided to have elective caesarean, which was very traumatic after what had happened the first time, but my first daughter, who's now sixteen, was born and was checked and was very healthy. Interestingly, when I'd had... they were very keen on checking me right up until she was born and checking my blood sugars. When I was back on the ward, like twenty four hours later, that was it - they didn't really know what they were doing, you know, I had to sort of sort out my own diabetes. And the dose of insulin had actually doubled as the baby grew, and I did have a hypo in hospital because they'd got the doses completely mixed up and were giving me, you know, twice as much as I needed. But they weren't that interested in me any more, or the diabetes. And then, I fortunately - I hadn't expected it - but I could actually... I was allowed to breast feed. Everything else had been so structured: I knew what day my child was going to be born because I'd elected to have a caesarean; I knew roughly what time she was going to be born, so it was quite unnatural, really. But I didn't mind - it was, you know, well worth it. So, I was actually pleasantly surprised that I could breastfeed, which, you know, was obviously a normal thing to do. But I did have to have help - I did have to eat more, I did have to be very careful while I was breastfeeding, because my blood sugar would drop while I was breastfeeding. And I was actually, I was - not so much when she was small - but concerned about whether, you know, she'd have any signs of diabetes. When she was born, I knew... well, I'd always been told that diabetics that had babies, the babies always turned out, you know, big, fat and red, like tomatoes, which didn't sound terribly attractive to me. But my daughter was six pounds two when she was born and lost weight. And when she was a few hours old, I said "can you test her blood sugar?", and eventually did, and it was two. And I said "I think she needs to feed", "oh no, she'll be all right", I said "no, her blood sugar is way too low". And my milk hadn't come in then, so they did actually let me feed her with a bottle to start off with. But after that, everything was fine. And I had to stay in hospital an extra day, because they thought - for the wound to heal - because they thought I had diabetes, therefore I wasn't going to heal, but no problem at all.

(18) And what happened in your third pregnancy?

The third pregnancy wasn't planned at all - well, I think we'd decided that we had one child who'd been born healthy and safe, and, talking over with my partner, I think he thought "we have one healthy baby, let's not try and risk having any more problems". So, I'd sort of thought "right, okay then", didn't think I was particularly fertile anyway. But when I was thirty seven, which was three and a half years later, I became pregnant again. In the meantime, I think my diabetes was reasonably well-controlled, and I knew - I did a pregnancy testing kit at home - so I was only about six weeks pregnant, so immediately I sort of tightened up on my control. So, I was well looked after to start off with. In fact, at one point, I'd go and see the obstetrician with my wonderful blood results, who then decided that they were actually probably a bit too low and that I was probably starving the baby, and I could actually relax a bit, you know. But I'm afraid that's me - one extreme to the other. So, my second daughter was born in 1992, really without any problems at all, except for that, with my second pregnancy, my eldest daughter had had her body scanned in utero and especially for heart problems. With my second daughter I had to go to Guy's a couple of times, because they weren't qualified enough in Oxford, so her heart was checked. And she was born and absolutely... she was fine, no problem. When she was... she must have been only a few weeks old - and I breastfed her for a few months as well - I had a hypo, and - at that stage they still took you into A&E - they don't now - took me into A&E to come round from. And I sort of came to, and was quite concerned - because I'd actually sort of gone out with the hypo because it was in the middle of the night - wanting to know where my baby was. And the staff came up and said "oh no, she's absolutely fine, we haven't got a lot on tonight" - you know, diabetic comes in with a baby, "the baby's so sweet, we've taken her off to, you know, show everybody". So, that was really the incident after that. There, again, I didn't have any problems healing; never had any problems wounds healing at all, so. Then, when she was about eight or nine months old, I realised that I could possibly be pregnant again and was quite concerned about it, and fortunately had an appointment at the diabetes centre. Went up there with a urine sample, and they confirmed that I was pregnant very soon, that day, because I'd said I didn't want to continue. So, with complete support from the diabetologist I was with at the time, decided to have a termination, which there, again, was... wasn't traumatic, it was quite emotional. After having one child that died, to then terminate a pregnancy is there, again, one extreme to another, but didn't actually cause me too many phys... well, no physical problems at all.

(19) Why did you decide to have a termination?

I decided I didn't want any more children. I've always believed that it's a woman's right to choose. It's just because of my... that I think I wasn't particularly fertile in my youth, I didn't ever think that I would be in a position where I would need to chose whether I had one. But I didn't... I had one daughter who was four, second child was only months old when I discovered I was pregnant again, so I decided, you know, my partner and I decided that we didn't want any more children. I had to go and see my diabetologist, who

thought that was the best course of action, and had said really he thought that was the best thing to do, because it was actually too soon after having my third child. But I'm not sure what he'd have said if I decided to go ahead, but that question didn't arise because we didn't want to have any more children. But I was supported, and, you know, take this opportunity to say I was supported by the medical staff in obstetrics as well.

Did you feel vulnerable being at home with small children and liable to get hypos?

Not at the time. Not at all, because I didn't actually... once I'd stopped breast feeding, I was actually quite well-controlled. I mean, in the past it has happened that one of my... my youngest daughter - who's now twelve, but this is a couple of years ago - she actually... if I go hypo, seriously hypo or I don't know that I've gone, it tends to be in the early hours of the morning - and a couple of years ago she'd actually - I must have been groaning - she actually came in and she saw me going hypo and got actually quite scared about it, and does occasionally say something about it now. And it's happened before. After that, during the day I went hypo and we had to have the paramedics here, and she got - not upset, but got concerned about it, and wanted to know all about it from then on. But it's not generally... you know, that was a couple of years ago, doesn't seem bothered about it at all.

(20) Can you talk a bit more about how your family has been affected by you having diabetes?

My immediate family are... they must be affected by my having diabetes. When I go hypo and I don't know anything about it, they must have been affected. And as I've just described with my younger daughter, I think she was a bit panicky about me being on my own for a while, but now she's absolutely fine about it - will leave me at the drop of a hat. But both daughters - we've always talked about it. And they've seen me have insulin - I've never tried to hide it from them, having insulin, and the syringes. And I've shown them how to do blood tests, you know, thinking that the worst thing they can do is be ignorant about it. My present partner is great. He takes it completely all in his stride. I have found it - because you now can give glycogen if I do go into severe hypo - I actually feel... it's interesting, because I actually feel more vulnerable when he's done it. I actually... and I, just recently, I've felt more like "oh god", you know, it must be awful for him. I actually feel that he feels that he has to do this for me - how does he feel about it? And he reassures me that it's not a problem. As long as I don't get too stropic, he doesn't see it as a problem. But I actually feel... I'm not happy about it. I'm not happy that he has to do it, but I certainly have no... He never mentions it, and we have talked about it, and I have actually said that I feel quite vulnerable that I have to rely on him so totally, and he just reassures me that it's not a problem, it hardly ever happens, and, you know. Interestingly, my mother was diagnosed as having maturity onset two years ago. She's always been quite concerned about me having diabetes, I think probably from the family history of things going awkwardly wrong as well.



But what's interesting is, when she was first diagnosed, I think she remembered my diet that I'd had to have and how strict it was then. So, my mother, bless her, had lost loads of weight; in fact lost too much weight, because she's, you know, controlled by diet, lost far too much weight, and was going over the top because she thought that the same things applied. Things have changed a lot since I was diagnosed anyway, and when she came to visit me fairly recently - I know she likes ice-cream, so I persuaded her it was okay, she could have some ice-cream - had to eat some ice-cream for her to show her that I wouldn't drop dead half an hour later, so. Unfortunately she has Alzheimer's, which I didn't - well, I

- (21) realised at the time, but didn't realise the effects of it. So, of course, what she does is, she has one ice-cream - and I've said you can have one ice-cream, you know it's absolutely fine; I'll have an ice-cream. Mother forgets she's had one ice-cream and has several. But she's fine. But my sister, quite interestingly, she decided when she was in her twenties - she's two years old than me - when she was in her twenties, she decided that she didn't want to have children. At the time, it was quite difficult to be sterilised. She didn't want to have to pay for it - the NHS were particular on who they would have - so she just told me, in a very blasé way, "well, I'm going to say - well, my sister has diabetes and my brother has schizophrenia, so I need to be sterilised". And I think she thought it was actually okay to say that, and we did have words about it. But she's fine. She never saw me hypo when I was younger, but she has been visiting and seen me hypo and is okay, just does what she can to help. I don't know how she feels privately, but with our family history of maturity onset diabetes, she expects to get it when she's older.

You mentioned, just now, allowing yourself an ice-cream. Can you remember when you began to allow yourself more things, and adjust your insulin accordingly, rather than keeping to fixed amounts of insulin?

Well, I never adjusted my insulin. I allowed myself, I think, as soon as... as soon as I left home I'd started having whatever... I ate whatever I wanted to eat, but I never adjusted my insulin; I wouldn't do it, you know. Half of me would go with it, but I wasn't prepared to adjust my insulin - it just seemed far too much faffing about to do, so I think... Four or five years ago, I decided that I wanted to lose weight, and had great help from a dietician at the Oxford diabetes centre. But, at the same time, it was suggested to me that I go onto using a pen - well, I suggested I use a pen, because I'd wanted to try before, and the doctor, at the time, said there was no point in me doing it and the nurses weren't very helpful. And I did try and it wasn't successful. But then I decided - at the same time as deciding that I wanted to lose weight - they were doing some research into some pens at the diabetes centre, so I started to have insulin four times a day, which I don't like, but. And then talked to the dietician about various - you know, eating... obviously what to eat and what not to eat - but there was various circumstances which arise, like going to a wedding, and what

would I do about, you know, the wedding was at two o'clock, I was going to eat at three, how would I do that? So, she actually advised me about adjusting my insulin to what I was eating. I don't do it that much, but I'm more likely, now, if I decide to do a day of blood testing, if it goes up, I'm confident now that I need to put it up and when I need to put it up, and if I'm going to have a big meal that I can have a little bit more. I just have to... you know, it's swings and roundabouts. It's a case of... for me it's a case of not getting too 'right on' about it, not being too obsessed by it. I mean, I have spoken to patients and to people at the diabetes centre who could quote you their blood sugar results from, you know, two years ago on a certain day. I don't want to be like that. I did say, at one point - because I've actually become more well-controlled through dieting and wanting to lose weight, not because I was asked to lose weight, but because I wanted to; nothing to do with the diabetes - and I actually said to one of the diabetologists "I'm turning into a professional diabetic", so... He said I wouldn't get paid for it!

(22) Can you tell me how the dietician helped you lose weight?

Well, the dietician didn't actually help me to lose weight - I did it all by myself. But I decided that I did want to lose weight, and I had seen dieticians before, who'd sort of just always said "well, don't eat this, don't eat that, don't eat fat, don't eat this". What I wanted was a diet that I could stick to, so I asked the diabetologist if I could see the dietician, and the dietician at the time, at the diabetes centre, was Pam Dyson. So, I walked in and said "I want to lose weight. I want you to give me a diet that I can stick to to lose weight", and she said "all right". And I was sort of... after I'd picked myself up on the floor I said "let's go back and do that again", I said "that's never quite happened before". So, that's what I did. She gave me a diet, and it wasn't... in fact, it was actually probably - apart from the biscuits and chocolate that I used to eat - was probably more than I was eating anyway. So, it took me quite a while to get started on it, but I did... for some reason, for the first time, I actually did stick to it. I was very good. And it took me, as I say, quite a few months to actually start losing weight, but then I managed to do it. And it did help having insulin four times a day, because it meant that I didn't have to have midmorning snacks, that I'd had to have before or else I'd go hypo at lunchtime, and I didn't have to have a before-bed snack any more, because I was having my insulin four times a day, so that certainly helped. But I reduced the amount of food that I was eating. We discussed exercise, and I said I wasn't going to, which was okay. And it took me about... probably about two years, I would think. I didn't actually set a goal in mind. I wanted to drop at least a dress size, and I managed to lose between two and two and a half stone. I don't actually keep to it now, but I am actually quite careful what I eat. And I prefer to see the dietician - a bit like weight watchers - I prefer to see the dietician about every five or six weeks now, just to check what I weigh.

(23) You say it was a diet you could keep to. Can you specify?

Well, it was one that I wasn't hungry. It did mean that I couldn't have chocolate

and biscuits, which I know is a strange thing to say if you have diabetes, but I knew I couldn't do that. I don't quite know why I decided to stick to it, but Pam... we did discuss lots of things about dieting, and... I can't actually remember what we discussed about dieting, but, you know, we discussed alcohol, because I drink alcohol, and she'd actually said "well, you know, you might have to give up alcohol if you find out you're not losing weight". But it wasn't... it was never a case of she said "you can't do this and you mustn't do that". She actually helped me to work my way round it. And when I'd started to lose weight - only about three or four pounds - I was so pleased that I actually managed to stick to it, and I think I probably got... I don't know if I got obsessive about it. I think, now, I think they wonder if I've got an eating disorder, because what happens is, I go to the dietician - whichever way it is, if I've... I try and maintain my weight. I have a day or two where I eat absolutely anything I want at all - probably more than I want - and then go back to eating a reasonably sensible diet. And I think she sort of encouraged me, that... and I found out for myself if, you know, just because you go off your diet one day, doesn't mean that that's it. You know, you just sort of take care the next day. I mean, one of the best pieces of advice, or what Pam and I talked about was, she said she was going to write a book about dieting, and it would only have one page or one title, and what it would say was "you eat a little less and exercise a little more, it's as easy and as hard as that". It's not easy and it's not particularly hard, you know, both of those things - it's not easy. And I don't mean to sound blasé about it, but it can be done. It's one of those cases - I did it, so everybody else can do it.

But you mentioned that you were going to refuse to do any exercise. What part has exercise played in your life?

Not a great deal actually. When I was at school, as I've mentioned before, I was actually very good at PE, but I don't exercise. I try and cycle as much as possible, but I don't... I think because my life has been... having diabetes, it's not so much regimented - I don't know what the word is. I've always had to... you know, diet's always played a major part in it, so I've always had to stick to a timetable of doing things, and, you know, eating at the right time, having insulin, or not doing this and not doing the other. So, I know that sometimes, as regards sticking to anything by choice, as in exercising, going to an exercise class, I'm not very good at it. And it all comes into - is that my personality because I've had to conform to a certain way of life, so I don't actually want to regiment it any further?

Can you describe a typical day in your life, now; say a working day?

A working day...

- (24) Mmm, typical working day - my partner brings me a cup of tea every morning between seven and quarter past. My daughters get up; I get up about the same time. I go into the bathroom. If I decide to do a blood sugar, I'll do one. I have my insulin. I come downstairs, prepare my lunch, have my breakfast - one and a quarter Weetabix, several cups of tea, one

cigarette. See my daughters off to school. Drive myself to work, which is only about twenty minutes. I'm a podiatrist - I have a very busy day. I have to have insulin at lunchtime, about one o'clock, which sometimes can be quite tricky because of the pressure of the service. It's quite tricky, but I do make myself - well, I have to have my insulin and allow myself enough time to eat. I will not treat anyone when I've had my insulin. You can wait half an hour after I've had the insulin that I'm on before you eat, but I won't treat anybody when I've had my insulin, because there have been occasions where I think that I can't - I shouldn't - practise, so I'm quite careful about things like that. I manage to snatch half an hour, between half an hour and an hour's lunch; an hour very rarely. I do a full clinic in the afternoon. I drive home, answer questions about what we're having for supper. Yeah, when I've answered the questions about what we're having for supper, I generally start cooking it; time it that, whatever I'm cooking, I allow myself a couple of minutes to leave the kitchen and go and have my insulin. We have supper altogether - the three of us; my partner's a chef so he's not around in the evenings. Do the domestic chores after that. Sit down; if it's a working day it'll usually be in the TV. I'm supposed to have some insulin about ten o'clock. I very often put off going to bed because I don't want to have my last injection of insulin, which sounds a bit strange, but I don't; I don't like doing the last one.

Why not?

I just don't. I just don't like doing it. I mean, it's taken me a long time to get used to doing it, and if I go out in the evening, it's always a question of "do I take it with me?". I think I don't like doing it, I think probably because it interferes. I can cope with the lunchtime one, although I did used to forget on occasion to have my lunchtime dose. I think it's from so many years of having two injections a day, and thinking that when I'd had the last one in the evening, that was it; I could forget about it. But having to have an injection between ten and eleven, to me, it's just - intrudes too much. If I go out of an evening, you know: "do I take it with me?", "how long am I going to be?". It just intrudes; intrudes too much.

(25) Will you talk more about your podiatry, and particularly what proportion of your patients have been diabetic over the years?

Until fairly recently, I would say probably about twenty five percent, thirty percent, maybe more - forgive me everybody out there - I would see people who had diabetes. Now, because we've moved to an 'at risk' service, I would say it's probably something like seventy five percent of patients have diabetes. Sometimes I - well, in the beginning, when I first qualified, I wouldn't tell people I had diabetes. And then it got to the point I would tell people, if I had - people who had maturity onset - if they would come in and go on and on about how awful it was to have diabetes, and they had to do this and they had to take tablets, I would actually say "well, I've had it since I was a child" and give them a brief background history, 'cause I just get so fed up of them feeling sorry for

themselves, and that's why I did. But, of course, that changed it, and then they ended up feeling terribly sorry for me, so I don't know if that was the right way to go. But as I've got older, obviously I do tend to identify more with people with having diabetes, and I have met more people the same age, through my work as a podiatrist, and seeing the patients who have diabetes of the same age that I have. And I still don't think it has... I don't relate to it at all. I'm not saying that I am any better, worse, or they are, but I don't tend to relate to it, and then, there again, I don't know whether that's a survival mechanism or not; I don't. I've seen some people who are the same age, if not younger, who have been in a far worse state than me, and I have actually been told that - you know, just commenting on it to various medical staff - that I actually - I'd have what I'd call a misspent youth; my diabetes has not been that well-controlled at times. It's okay at the moment. I don't think it's brilliant, but it's actually it's all right - that people who have diabetes fall into two categories. I'm talking about people who have type one diabetes such as myself - that there are some people who are more prone to complications of diabetes, retinopathy, problems with their kidneys and various other problems that you can have with diabetes, and those such as myself who, fortunately, haven't got too many problems. I have a little bit of retinopathy, but my eyes are not affected. My kidneys are absolutely fine. I've taken part in research and I asked if I could have a tape of it, but my kidneys are absolutely fine. My circulation's fine - I have no problem

(26) with neuropathy, the feeling in my feet.

Does that make you feel virtuous, in some way, that your feet are in a better state than people of the same age as you?

No, I just find it amazing, actually. But sorry, what I was saying before was, so they've now decided that there's people, such as myself, who've had diabetes for a long time but haven't got that many complications, hardly any, and people who have. And their thing is now to find out what it is about people such as myself - is there something there, is it - whatever it is - about my body makeup that makes it that I haven't got - I'm not saying I'm not going to get them in the next thirty years - but I haven't got many of the complications, where someone who's probably been as well-controlled - if not better controlled as me - have problems? And I would think that's the next big... one of the major things that they need to find out. I mean, I realise that I have been very fortunate. I don't know; there again, maybe it's because, at the right time, I got myself more under control, which sounds very sort of... I don't know whether it's moralistic or whatever, I don't know. Maybe I was just fortunate it's my body makeup.

You mentioned a consultant once called you naughty. Have you found that there's been a kind of moralising element surrounding diabetes during the years that you've had it?

Oh yes, oh absolutely. When I first started off, and, as I said, when I came to Oxford, you know, "you've been quite naughty", but it's surprising what you can get away with when you smile on your face. I have never had a problem with

medics; partially, I suppose, because I've worked with medics, but also because I've been dealing with medics since I was thirteen, you know, so. Except for the one guy in Manchester, who was really horrible and was telling me I was, you know, I was going to go blind and so on, nobody's actually been that horrible. And when I was told I was naughty, it was said with a smile on man's face, and, you know, and in the next breath he said "whatever you're doing, carry on doing it, because you're absolutely doing... everything's okay", you know. And I said to him "oh, I eat chocolate", and he said "don't care, you know, your blood sugars are all right, your HbA1 is fine - carry on".

Reflecting over all the years you've had diabetes, have the attitudes of doctors and nurses changed?

Yeah, I mean, obviously I was only a young child when I had it, but then, even then, I would imagine in the medical profession as a whole, it was a bit us and them and the consultant was god and so on. But yeah, I think things have changed, and I've obviously become more educated generally and in diabetes, but lots of things have changed in diabetes. It's now, doctors will accept that you - and it's been said to me on more than one occasion - "you probably know more about it than we do", which is

- (27) sort of okay, but you then think "well, why am I coming here then? You know, if I know more about it than you, what's the point of me coming?", but then that's probably me. But when I started off, it was you had to use a glass syringe that had to be kept in surgical spirit, you had to boil it once a week, you had to do urine tests, which I've gone into great detail about, this awful Line diet. And through the years, things... I think they actually are more willing to listen to how it's affecting your life, but then I think you still have to push it a bit. You have to sort of convince them that you do, you know, you have got a reasonable amount of intelligence and that you can. I mean, I still speak to elderly people who... and I say "well, do you have diabetes?", and they say "I don't know. They said I'm on the borderline. I don't know if I've got diabetes", and then you find out that they're taking a tablet for diabetes, and they don't know they've got diabetes. So, things aren't quite where they should be. But I've actually always asked questions about it, or, you know, not put up with a lot. But attitudes have changed, and, you know, you can use a pen syringe now, which is supposed to be like a biro pen; it's nothing like a biro pen. It's another one of those things "oh, it's terribly wonderful to have a pen syringe". It is - they're great, but it's nothing like a pen; it's about four times the size of a pen. And blood sugars, testing blood sugars - they can now do the HbA1, so they can tell you what your blood sugar's been like for the last six weeks, so you can't get away with anything, which is a good thing. And testing your blood sugar is a lot easier than even when I started doing it, you know, whenever it was. You can now buy a machine that it will only take twenty seconds; you can probably get one that takes fifteen. I don't think there's a big deal of difference between

thirty seconds and fifteen seconds, but things have changed as regards that. And they now say - when I first was diagnosed, you couldn't have anything with sugar in at all, and you had to keep your carbohydrate level down. Now they say "reduce your sugar intake", which to me was a total revelation that they were turning round to people and saying "just keep your sugar level down"; I thought that was amazing. I mean, I've always done that anyway, or for the last twenty, thirty years I've done that, but they're actually telling people that's what you should have to do; you don't have to stop altogether. They're actually realising that people have lives to lead, and it's better to go with how people live and what their lives involve, and that you can't predict... you can't be prescriptive and say "do this, do that", 'cause it won't work. So, you're better off going with how people actually lead their lives.

And have you noticed any

(28) changes in attitudes towards diabetes in society?

Well, there's a lot more of it about. I mean, there's this thing where, you know, there's a million people going around undiagnosed, which is quite weird actually, because I heard that about thirty years ago, so they've not been discovered yet, you know. But with the National Framework for Diabetes, a lot more medics know about diabetes, and I think... or whether it's just people around me know more about diabetes from myself. But I still think that people have... they're not quite sure about it. They know it's something to do with sugar and not having it, but they, you know, you do have to explain still what a hypo and a hyper is, and when you need your insulin and when you need to eat, and people still find it a bit confusing. But they are aware more of diabetes, I think, and that it's not quite as bad as it was. But then, you know, in most chemist shops they advertise that you can go in and be tested for diabetes. It's all to do with your waist size apparently.

You've reflected a little on how your personality might have been different if you hadn't had diabetes. How do you think your life would have been different? Would it have been different?

I don't know. I mean, I was actually, as I said before, a very shy child, and so I'm presuming, because I've had to sort of force myself into certain situations, maybe it's just helped me to do that, or maybe it's just a case of maturing anyway; I don't know, there's no way of knowing. But I would, actually, like to talk to a psychologist or someone, just to talk about it and to see what they come up with. I mean, you know, I do believe people are the sum total of their experiences, so I guess it has; it must have changed my life. I don't know how my life had been different, but maybe I wouldn't have felt that I had to rebel quite as much, because, as I said before, that I had to conform and do things at a certain time, and I would actually go against that now. You know, I still can't be one of those people that, you know, cleans one room one day, cleans the same room the same day of the next week, because it's too much, you know,

it's too prescriptive, I can't do it, so who knows?

What keeps you going?

I'm not entirely sure what keeps me going, actually. I have felt, I must admit, just recently... the pressure, apparently, has gone up behind my eyes. I know I have a little bit of retinopathy, and I have to go back and see about glaucoma. And I guess, maybe for the first time, I have thought "what is it?". You know, my kidneys are okay, most things about my diabetes are okay, and I did think, just recently, "what is it that's going to get me?",

(29) and then thought "there's not a lot of point in worrying about it, you know, deal with it as it comes". I mean, I don't... I've never worried unduly about what happens with diabetes. Firstly, I think it was because I thought "well, it's not going to happen to me", or I just ignored it, but. And I've been asked, in the past, by various medics to speak to people about having had diabetes. In one case, I was asked to speak to another pregnant woman whose diabetes was not very well-controlled, and she, as I say, she was pregnant. And because I'd had an experience of being not well-controlled in diabetes, I was asked to do it, and I couldn't. I felt I couldn't do it, because whatever's happened to me has happened to me; it doesn't mean that it's the right thing to do for everybody. I mean, I've learnt a lot about myself and about diabetes, and I could maybe sort of suggest things, but I would never say that what I've done is the right way to go about it, because... Although, you know, if you're on insulin, there's lots of people on insulin, but everybody - it sounds terribly twee - but everybody is very different, their circumstances are different, their bodies are different, so I wouldn't like to do it.

So, no tips, then, for somebody who's just been diagnosed with diabetes?

Apart from it's not that bad. Don't let it stop you doing anything. Let it stop you doing things if you want it to stop you doing things, but it doesn't have to stop you doing anything. I have done lots of things. I have travelled round quite a lot, I have travelled abroad without having anywhere to stay. I once was in Italy and camped without a tent in an orchard - I just made sure I had some food with me and my insulin, and never stopped me. But, as I say, it can stop you doing things if you want it to. If you don't want it to, there's no reason why it should.

And would you advise them to give up smoking?

After some thought, yes, you know, definitely, I would. Being a healthcare professional - definitely I would advise anyone to give up smoking, and I would advise myself to give up smoking, I guess, but I'm not quite there yet - but don't start; give it up.