

22. Julia

(1) Tell me about your background.

Well, I lived in Coventry with my sister, who's three years older than me, and my Mum. My father and she split up when I was five, so mainly brought up by my Mum, who seemed to be very busy doing lots of different jobs: administrating, cleaning for friends' houses, making me dancing costumes. My sister went off to train as a nurse, which she's always wanted to be, and my Mum remarried when I was nine, so we gained some step brothers and sisters for a while. And then I went off and did teacher training in Birmingham at Westhill College, taught full-time in primary school for a little while, and then diverted more into dance, because I'd always danced as a child, and started to move into that specialism. While I was at University, I met my husband, who works for the BBC and has done for twenty years now. And that caused our - well, my only move - from the West Midlands moving up to Newcastle a couple of years ago.

What did your father do?

Well, when he was married to my Mum, I believe he worked in insurance. I think he was a bit of a flitter from what I can gather, 'cause since, obviously still having contact with him, he moved to run a B&B with his new wife, but focussing on breeding chickens and Khaki Campbells and geese, which my children love very much. And now he produces hay for horses, so. And my step Dad - as I say, when I was nine my Mum remarried - and he was a foreman at the Morris, the car factory, in Birmingham. . . no, in Coventry that would have been - yes, before I was in Birmingham.

And is there any history of diabetes in your family?

Well, it's interesting, because a little bit of that is sort of hearsay, and I'm not sure how accurate my Mum is. But she said that on my father's side, my father's Mum's Mum would have been officially diabetic, but it was prior to insulin being invented. Now, how she knows that, I'm not quite sure. But on my Mum's side, my Grandma had maturity-onset diabetes. My own Mum is now eighty two, and, interestingly enough, a few weeks ago they were querying whether she was diabetic. But, in fact, she had a glucose tolerance test and it came out as normal, but it wouldn't surprise me if she's moving towards that.

Would you say you were reasonably well-off as you were growing up?

I wouldn't say we were well-off. As I say, my Mum seemed to be working all the time in various. . . sort of two or three little jobs, to keep things together, and, I suppose, at the time, you know, as a single parent for quite a few years as well. My sister and I both took exams and managed to get into grammar schools in Coventry, but that was because there were means tested places, and so that meant that we could afford it. I was the first person to go to university in the family. My sister focussed on the nursing career, and subsequently has done a. . . we've both done Masters, and. . . So yes, it was tricky. We weren't well-off particularly. We weren't poor, but we certainly weren't well-off.

(2) Tell me what you did after university.

Okay. I left university in '85, 1985, and started teaching in the September, but in fact got married the month before. So, once I left university, I got married and started my first teaching job in primary school in the same year. So, for the first four years of my married life I worked, to begin with, as I've said, in the primary school, but moved across very soon into dance specialism. And I'd done theatre studies A Level, and so in some places I would work in drama and dance combined. And I began to freelance around the different Birmingham LEAs, and then I worked as a dance artist in schools doing short term projects. And it was an exciting time, then, because dance artists in schools was just kicking off and there was a lot going on; there was a lot of interest. And I got work working for the Hippodrome in Birmingham as liaison, working - lets say we did Cinderella as a pantomime in the Hippodrome - I would go into schools and have great fun doing dance workshops about the ugly sisters and Cinderella, and in the nurseries. And I actually worked right up through in adult ed as well, doing things like tap classes and jazz, and having a lot of fun with adults as well. And there was also the Birmingham Royal Ballet came to town, which was great excitement, and I think that was shortly after I had my first daughter - when I was married about four years, Rebecca was born in 1989; that's right. And so I did do some part-time work still, and the ballet coming to town meant that I could work on education packs at home, which was great while Rebecca was tiny.

Tell me about your pregnancy, then, in 1989.

Right. First pregnancy was very exciting and planned and great. What wasn't planned or expected was within the first urine sample that the GP took to tell me I was pregnant, there was "high sugar" was what he said. And so that - I discovered I was pregnant in December 1988, so in February I was put on a no-sugar diet, when there were three pluses of glucose in my urine at that time. And then, moving through, about thirteen weeks pregnant I had the glucose tolerance test, which at that time was described as high, but still in the normal. And then was repeated at twenty weeks pregnant, in the April, and that showed what they called a true diabetic curve, and that meant that not only was the sugar was banned, but the carbohydrate was being reduced. And in the following month, at twenty five weeks pregnant, I was actually put onto insulin for the first time.

Did you think that the diabetes would last beyond your pregnancy?

That was interesting, that I think the GP, at the time, was wanting to wait and see. But my consultant at the hospital, from the beginning, I think he was taking a sensible approach with me and saying there is a

(3) good chance that this isn't gestational diabetes and therefore wouldn't go away, I think because it was discovered so early in the pregnancy. I think, normally, gestational diabetes shows itself a bit further along, when you're big and heavy and you're under strain, whereas, as I say, it was in

that first urine sample. And really, I have often felt that perhaps actually getting pregnant was in a way good, because possibly the diabetes was even there before and had gone unnoticed.

Which hospital was this?

Now, let me think. The first daughter was born in Sorrento Hospital in Moseley, which was a lovely small hospital, which has since closed, but my diabetic care began at Selly Oak Hospital in Birmingham. And they did manage to liaise quite well. I do remember an awful lot of appointments, but there was a key figure, a sort of heroine for me in that, and that was the diabetic health visitor.

Tell me about her.

Sorry, I'm not sure whether you want me to name her. Yes, Pam Riley was her name, and she - I suppose it's necessary that you have the consultant, and then you have the nurse, and you have this sort of more feeling, understanding person to relate to. And it was certainly what I needed, because - well, I was, I think I was twenty four, or was it twenty six? I can't remember, but it was my first pregnancy, and then I had the shock of being told I was diabetic as well. And I remember having just been told I was going to go on the insulin, and then moved into the room where Pam Riley was, and she said "oh, hello dear. How long have you been diabetic?", and I said "about thirty seconds, I think!". So, she was just great. And I had, actually, quite a phobia of needles, and I think that was the first thing that was really sort of going on inside of me - "oh, insulin means needles". And I was thrilled at discovering that it really didn't hurt when I did my first injection. I didn't believe her, of course, when she said it wouldn't, and she showed me the needle and said "oh, it's very fine dear, very fine", but it was painless. And I began with the very small syringes, and with a bit of practice - yes, I think I did use an orange at first. And I still remember sort of looking down at my thigh, and resting the side of my hand on my leg and pinching up a nice flabby bit, and thinking "this is definitely going to hurt", but then actually not feeling it when I plucked up the courage to do it. There was that moment that I couldn't believe I was about to do it. But yeah, she was very good for me, particularly - all round really, not just with the diabetes, but with the pregnancy. And I remember, always, she kept repeating to me "the needs of the mother are paramount", and she was a real professional. She was at a time when clearly there was a new wave of diabetic nurses coming through that had gone and done their six week training course, and you could sort of tell that she was the 'old school' perhaps it would be called. But she almost only had to look at me and she would get my blood sugar right. She would sit me down and she'd say "oh, you're looking a bit off colour, dear", you know, "let's give you a cup of tea and test your blood sugar"; and there I was - two-point-five. And she was absolutely right - I needed a biscuit and some sugar in my tea. And she just really helped me on a sort of emotional level.

What other training did you have about monitoring sugars or diet?

Right.

- (4) Over the years - I've been diabetic fifteen years now, yes, my first daughter's fifteen - I do recognise that it's changed. It's sort of gone in waves. At first I was taught very much in the - I've forgotten the name of the carbohydrate portions that we would call exchanges, that's it, that was it - we were taught exchanges then, which was equivalent to ten grams of carbohydrate. But we weren't really taught with numbers - we were told what was approximately an exchange: a slice of bread, an apple, an orange, so we knew things that were roughly the same; an egg sized potato. And so I was taught - generally I was looking at my plate and trying to make sure there were the number of exchanges on it that I was having my dose for. And to begin with, they just asked me what I normally ate, and fixed the number of exchanges to what I ate. So, my intake was not reduced in terms of carbohydrate that I was eating - the insulin I was told to take was levelled with that. But, of course, then there was a lot less freedom with the insulin regime, and also with the things that diabetics were supposed to eat and not eat. And that has moved over the years to become - "oh, we don't count exchanges any more" I was told in one place. But then, in fact, it was just a sort of replacing of exchanges with portions, or sometimes you would have advice that would be "oh, just look at the size of the meal and see if it's roughly five exchanges - or five portions - or fifty grams of carbohydrate", whichever sort of particular term was used by that health professional. And also, I think I remember right at the beginning, I think diabetic products were okay - we should use sugar-free drinks and we should use sugar-free chocolate, and things like that. Whereas slowly, over the years, it has been "no, it's much better to have one square of proper chocolate after your meal than consume a whole bar of diabetic chocolate", because I think that's what they think you're going to do, because you can eat a whole bar. But it's going to, of course, have a lot higher fat intake, quite apart from the sort of effect of having lots of artificial sweeteners,
- (5) which is quite dire. But it all seemed rather vague and changing, until, actually, when I moved a year and a half ago from the West Midlands - although I have no complaints about the care at all there - coming up to the North East and moving to Newcastle meant that I was introduced to the DAFNE course, and that's been much more specific and much more empowering.

We'll talk about that in some detail later. But going back to your diagnosis - can you remember how you felt at being diagnosed with diabetes?

Yes. It was a surprise, of course, 'cause I was focussed on having a baby. And I think, in some ways, that actually did help me, because I was very aware straight away that I had to get this right because I was pregnant. It was almost not looking after myself - it was looking after the baby. I was sent an article, an awful article, about how babies can be deformed, and have terribly wrong number of things in the wrong number of outlets and inputs to the heart, and all sorts of strange deformities. And that did scare me rather, and so I had the

motivation of being pregnant to focus on, and I think that helped me. I didn't wallow in self pity or anything, whereas over the years, from time to time, you do. I do have moments, not very often, but moments where you are just absolutely fed up of it, whereas, at the beginning, having all that to focus on was good in terms of control. It did scare me silly, because I was facing a labour, and I was already scared of, you know, the thought of delivering a baby, and then I had all these doctors telling me "well, you'll need an insulin and glucose drip, and you'll need to be monitored". And I was wanting this very mobile birth, and all sorts of - I didn't want any anaesthetic, and, of course, all the medical people were saying "well, an epidural - I would prefer you to have an epidural. An epidural would make it much easier and ta-de-da-de-da..."; making life easier for them, of course. Whereas part of my labour plan that I wrote and had thought about before, that was one of the things I didn't want. I was involved with dancing a lot - the last thing I wanted was a needle in my spine. Even if it was only a

- (6) bad headache and a backache that I got after, I didn't want it. I was appalled at one time - I was told that, being a dancer, my muscles would be more likely to get in the way. And I disputed that absolutely, because I felt being a dancer meant that, having superior muscle control, I'm much more aware of what my muscles are doing. And, in fact, I was very pleased to have only a one hour labour. They did use a Syntoxin syntocin drip, and about one hour later the contractions began, and the baby was born one hour after that, with no pain relief and with no injections, which I was very, very proud of, because they were promising that they would, you know, they'd tail off the epidural and allow me to push etcetera. I did have some good antenatal classes and breathing techniques, which I still remember the Thomas the Tank Engine breathing technique!

What is it?

It goes "ooh, ooh, ooooooh - ooh, ooh, ooooooh", and I think by the end of it, the third one was very much the "shhhh - shhhh" hissing through the teeth technique. So yes, I did need those techniques, but I was very glad not to sort of be pressured into the other things, which I hadn't wanted. There was a concern... I mean, I managed to stay mobile. They flexed where they could in sort of taking off the monitoring belt so that I could move around. I think that there was a panic as the baby was actually coming out, because she had her hand on her head, and everyone's thinking "diabetic mother, big baby - oh no, what shall we do?". And I think there was a panic, and so I had an episiotomy too early and ended up having to have three units of blood, 'cause a few days later, you know, I lost a lot of blood, because a blood vessel was actually cut through at that time. And so that complicated the first few days, with blood transfusion and then with lots of blood around the episiotomy, the wound was infected and had to be re-stitched, and all sorts of things like that. And I was feeling a bit cross about that, that people were sort of saying "oh, diabetes - we're going to have to do this, do this", and it wasn't really necessary. And I think the word diabetes seemed to just create a bit of panic in the labour situation, which,

in hindsight, was unnecessary, and I think even now that probably wouldn't happen.

Was it a big diabetic baby?

Well, no, actually. Becky, my first,

- (7) was eight pound eight and a half, which I think is sort of fairly middle of the road. As I said, I put quite a lot of care into my blood sugar control. When I had my second baby in 1994 - that was about four and a half years later - of course my control, then, was accompanied by controlling another child as well, and so I don't - well, I know that my blood sugar control wasn't as good. And when I came to that birth, my second baby, Grace, was ten pound seven. And I remember by then - all three of my babies have been induced approximately two to three weeks early, because that's the norm with diabetic mothers. And I didn't mind that; that was fine. It was quite comforting having a date when you knew you were going in to have your baby, and watching all my friends go weeks over, and say "I want my baby out"! So, I didn't have to go through any of that, and I didn't mind. But I remember with my second, I was the one that was hollering "get this baby out! Can I have this baby out?!", because of the scan measurements. Of course, all the technology tells you how big your baby's getting, and then the consultants try to calm you down. And I remember him saying about, only a few days before I actually gave birth to Grace, that I had a seven pound baby in there, and I made sure he was told that he wasn't right, a few days after that.

Going back to your first pregnancy, and you say the word diabetes caused panic. How much did people know in the Sorrento maternity hospital about diabetes?

Well, I would be surprised if the level of expertise was very high. Obviously this is fifteen years later now and I'm guessing really, but all my diabetic care, as I say, had happened via Selly Oak. And the consultant, there, I believe he was in contact and coming across, but the work, more recently, seems to be much more integrated, and so I think, you know, they were a maternity hospital. And all I can say is that, you know, the midwife did dive in too soon, in my opinion, so, I think... But, of course, I didn't know that at the time. But now, having asked lots of questions, you know, it would have been fine. It would have been safer to wait and not cut through a blood vessel, but... So, maybe closer communication and having diabetic specialists

- (8) there wasn't really happening. I never got the impression there was expertise there, because the care was quite separate, until the time that I went to antenatals at Sorrento and then I went to diabetic clinics at Selly Oak.

Can you remember how you managed with the first few weeks of breast feeding, so newly diagnosed as diabetic?

Yes, it wasn't bad. As I said, the most difficult things were - I think it was

about, yeah, day four - having to have, there's my milk coming in, and at the same time I'm having to be re-stitched and have three units of blood, which I could have done without. But the breast feeding was fine. I remember, Rebecca was unfortunately a very colicky baby right from the beginning, but I breast fed each of my three children for six months each, and thankfully didn't have any problems with that.

Did you have any problems about keeping to a sugar-free diet?

Yes. If I tell you, before, when I was teaching with a friend in Birmingham, we very often after school we'd go to the cream cake shop. And we'd buy a cream cake for immediate consumption, we'd buy a cream cake to have with coffee at my house, and we'd probably buy a cream cake to keep for later! And we used to put the three bags all into one bag, so no one could see the evidence of having three cakes! That was just on really bad days you understand. So, I did have quite a sweet tooth. And it's funny, I was reflecting on this and the role of personality in diabetes, because a very helpful friend, who was diabetic, had been diagnosed for a number of years before I had, was very disciplined in her diabetic care. She was a different personality to me, and she was also a medical person: she was an OT looking after stroke patients. And I used to envy her, and I think I probably still do wish that I had that sort of personality, where I... and also not the sweet tooth, because she was able to control, seemingly without effort or regret, the sugar. I did do it, I was a good girl, but I think, as I said, the motivation of being pregnant is something that helps you a lot, whereas one of the phrases that was used at one time to describe me as a diabetic

- (9) was atypical and unstable! I think they were talking about my diabetes and not my personality. So yes, it's been a struggle. And, in fact, the regime I'm on now following DAFNE is just great for someone like me. Being a dancer as well, of course, you have fluctuations of levels of exercise, and so, and having three children means you're very busy, and things that are flexible suit the family life. They suited my career - things were juggled depending on dance lessons, 'cause you don't want to have to eat before dancing, or you might feel mega hungry afterwards. So, because now, I'm on - I have been for quite some years, even prior to doing the DAFNE - but on a regime where you take fast acting insulin before each meal, and then you have a long acting basal dose through the night. That helps, and, in fact, I've often thought I prefer that to being diet controlled and not having to do injections, and I would also prefer that to being on tablets. So, although people say "oh, four injections a day, how terrible", for me, it means I can have a flexible life. And if I see - well, as the diabetes nurse that taught on the DAFNE course, she brought in the chocolate cake and said "if you can calculate the units you need for that, then you can eat it", so that's how I view... You still get people tutting at you. I was in a Church and there were about five GPs in the congregation, so whenever we had a function, I felt like they were all watching what I ate. And then some of them would come along and say "tut, tut, tut - should you be

eating that?”, and sometimes I thought “oh no, I should be being a good girl”. But, I think, basically, if I can work out what my body should be producing for the food, obviously we’re all supposed to be on healthy diets - low fat, low sugar, high fibre diets - but that’s not just the diabetics amongst us. So, it can be a struggle.

You use the expression, you know, “I was a good girl”. Did any of the members of the medical profession sort of make you feel that there was a moral element to this?

Yes, it’s funny. I remember a comment once, it was about we - “we aren’t doing very well, are we?”, or “we aren’t being very good, are we?”. And I thought to myself, “well, you’ve actually got nothing to do with it. It’s me that has to do this day in, day out actually, so I don’t know where you think the “we” comes in”. So, there was... I mean, of course, they’re trying to be helpful, and it is something that is patient managed after all. I never really felt told off, but, you know, people want to be able to help you to look after yourself. And I think, at times, you know that you’re doing something that isn’t ideal, but, you know, if you’re having a bad day and you’re fed up, then chocolate helps!

(10) So, now can you talk about life with one baby, part-time dance work, and managing diabetes?

Yes, well, I think I mentioned that my personality is one that is a bit here and there. I’m not a disciplined steady regular type, and my life has never been like that either. And working as a freelancer meant that I didn’t go into work at nine and came home at five and did regular things as well, and, of course, toddlers are never particularly regular in anything. And so, the diabetes - I never have actually allowed it to be a controlling factor. I think, maybe, people who - I mentioned I have a friend who’s very regular, and I think is... her diabetes, perhaps, does dictate her life. Mine has never been like that, and it’s sort of had to fit in with what’s going on in my life. And so, I think, perhaps, because of that, the diabetic control is never stunning. But I don’t think I was very good at it really. Because of personality, I’d be arranging lots of things that, probably, sensible diabetics wouldn’t arrange in the timetable that I used to arrange them in. I’d be, you know, dropping off Becky here, taking on a dance or drama workshop there, volunteering to do some choreography there, and so, yeah, my life is a fair sort of dash around, really. I’ve got involved with running a youth work, and, you know, spending time with young people; again, teenagers aren’t very predictable. So no, it was a bit all of a mish-mash, really.

(11) Yes, in about 1991 - I’d been diabetic for a couple of years, and I’d been on very low doses of insulin all that time, and, I mean, sort of like two units and two units, and then four maybe for a big meal in the evening, which was a very small dose compared to the rest of the clinic. And so they did try to see if I could take tablets to find out if my pancreas was actually producing any insulin at all. But within a very short space of time - a week or two, not very long - it was clear that no, tablets weren’t



going to work, and I was back on the insulin. And I don't remember being disappointed, actually, because of the flexibility that the injections gave me, and I really did need flexibility because of my lack of regular lifestyle.

So, in what way were your injections flexible? Were you altering the dosage all the time, or?

Yes, I was. I can't remember quite how soon and how much, but I do remember a time when I was advised that I was actually changing it around too often to even begin to allow a pattern to emerge. But that was back in the 'old days', let's say, when I was on insulins that weren't as good at mimicking the body's insulin. Now I'm on Humalog Lispro, which has far less of a tail off. I think it was Actrapid that I began on, which, although it was a fast-acting, would still be around for a while, and so you'd end up with insulin still working long after your meal, and so you have, sort of, more hypos. Now, being on something which is much more closely linked to acting on the food and then dying away, it's great, because, in fact, you can wait and see what you're going to eat and decide there and then on how much insulin you're going to take. Whereas, in the early days - I think at one time I tried a Mixtard, a mixture, where you're just taking in the morning and the evening, so that was predetermining at what times I would need to eat and how much I would need to eat. Absolute disaster for me; I would be hypoing all over the place. I do remember one time with a Tesco's trolley - thankfully my husband wasn't too far away - but I definitely needed to have a sit down. I've never been hospitalised or comatose, or anything as serious as that, but I have had one or two occasions where I've had to be helped to the

- (12) orange juice drink or the Lucozade drink. It's interesting in itself, that, actually. To begin with, I was told that mini Mars bars were the things I should keep on my person, and it doesn't take long for a mini Mars bar to get very squished up and squelched up in the bag or in the glove box of the car. And Lucozade tablets, at the time I think that was mentioned, but I used to find them very unattractive, like chewing on a piece of chalk. Whereas more recently, the advice has been to take pure orange juice, and it's easy to have cartons of orange juice around the place. But yes, two or three occasions I've needed help to get that down my neck as quickly as possible. The girls - I was just talking to my daughters about, you know, "what's it like having a diabetic Mum and how has it affected you?", and my middle daughter, who's ten, is particularly sort of cross with it, I think. She's like, well, she said "it's poo. It's horrible. Tell them it's terrible. It stinks!", because she feels for me a lot. And I suppose she catches times when I've perhaps had enough of it, 'cause I probably would verbalise that, 'cause I don't keep very much on the inside. But we did have a laugh remembering a time I was doing bedtime story, apparently, and was actually quite hypo. And we were reading a story - I can't remember what the story was - but the girls love to mimic me, 'cause I was going "shejejeje, shejejeje". And Paul was asking "are you all right, do you need

something?”, and I’m going “shejejeje, shejeje”, like a sort of drunk person, telling him to shut up. And he was coming to try and help me have the orange juice, and I was sort of practically batting it out of his hand. But that was to great amusement of my kids, anyway.

Was it at all frightening to think you might be completely out with small children?

No, actually. Thankfully, I have always had good signs of going into a hypo. I do remember fairly early on in my diabetes, there were people who were not getting warning signs that, I think, had been on the bovine and porcine insulins. The time I was diagnosed, as I say... 1985 I was married, it was '89 that my first daughter was born, they... some people were still on those insulins, but I was put onto Actrapid, which was an engineered, you know, a synthetic insulin. So I... whether it's because of that or not, I'm not sure, but I've always had pretty good signs, so I've never felt afraid of,

(13) you know, being out of it with the children. Grace is ten, and she's known for quite a few years what to do if she were to find me. Obviously Rachel, my youngest, is only three, and she understands very little about it. But, in fact, she likes to use it. She'll say “Mummy, I need one of your sugar tablets. Mummy, I need one of those to make... - I'm hypo, I'm having a hypo Mummy”! So, at the moment, for her, it's just a nice excuse for a glucose tablet, and she actually likes the things!

Tell me about your other two pregnancies.

It's funny. My second pregnancy, I can't remember very much about it at all. I had a four year old, and I think it was just consumed with that, really. Obviously my control wasn't as good. I do remember one slightly disparaging, kind of almost of a tut-tut comment when my second baby was born at ten pounds seven, and I heard a muttering about “bad diabetic control...”. It was a man, of course, and it was a doctor who isn't diabetic and doesn't know what it's like looking after a four year old and being pregnant as a diabetic, so I didn't pay much attention to that. But it certainly is... it's just another juggling act. And, in fact, Rachel, my youngest, there was a seven year gap between my second and third, and - how heavy was she? She was about nine eight, sort of in the middle of the other two - and so I think things were perhaps a little... I was more experienced as a diabetic, more experienced as a mother, still not much of a better cook! But things were sort of calmer by then, I think, and the pregnancy, I hardly remember them. I think I benefited from a more unified care, in terms of not having to go to so many different clinics and appointments. But I think they seem to be keener on quite a lot of scans, more so in this last time. I was having all sorts of interesting scans and tests while I was in the sort of later weeks of pregnancy, that seemed new to me.

So, describe this unified care, then. Who provided it?

Well, by that time it was at the Queen Elizabeth Hospital in Birmingham. Both Grace and Rachel, my second and third, were born there. And so, I suppose,

because they

- (14) were in the same building. . . yes, even though the diabetic care happened at Selly Oak, once I was pregnant there was this wonderful lady consultant at Queen Elizabeth, who was a - from my point of view, as a consumer - I think she was actually a diabetes obstetrician, which I don't think existed at the time I had my first baby. So - someone might tell me I'm wrong - but from my perception, I was seeing an expert in childbirth and diabetes in the one person, and the surrounding team. They were all there together - the dietician, and the obstetrician was. . . she was also the lady that was advising me about the doses. And there were regular HbA1cs happening, and the test results were much quicker. I mean, in the fifteen - no, not fifteen years - it's about a twelve year gap from first to my last pregnancy, you could tell that technology had caught up a little bit as well. And it just made you feel more secure, as well as simply taking the stress out of pregnancy by having less appointments, and toddlers to drag around, or, you know, time off work to organise. So yes, I felt a lot better. And, in fact, my third labour - the birth - it was a minor thing, and I can't even remember whether in my second pregnancy, second labour, as well, it wasn't automatic - by the time I had my third, it wasn't automatic that I was going to have to have a glucose and insulin drip. It was more "let's see how long the labour lasts", "let's see how things go". And, I mean, during the fifteen years since I had my first baby, I have been in hospital for two or three other occasions, and there seems to have been a shift in general over that time. Whereas, early on, you'd go in and you'd have to hand over everything to the staff - you'd have to hand over your insulin and your test kit. And it was almost automatic - "diabetic", you know, "get a drip hung on them straight away". And quite honestly - I can't remember what I was in for on one occasion - they just made such a mess of my diabetic control. Within minutes my blood sugar was seventeen, which is much higher than you want to be. And I was perfectly capable still of - there was something wrong with my toe, I think - and I was still perfectly capable of doing my blood test and my
- (15) injection, but no, they were in the mindset still of having to take it over. Of course, they were only doing what they were told - I'm sure the nurses would have been told to do that. Whereas more recently, and in the labour with Rachel when she was born in 2000, I don't believe I had anyone interfering. I was still taking occasional shots of my insulin when I needed to. As it was, I ended up having to have an emergency hysterectomy and nineteen bags of blood, which. . . I was allowed to feel just like a normal patient. I mean, yes, of course, by that time they needed to be monitoring my diabetes, but the actual labour and delivery of the baby was perfectly fine, and that was the least of the bother at that time. And so, I have witnessed change, and fifteen years isn't very long, really, to witness quite a lot of change, I think.

Have you noticed any changes in the attitudes of doctors and nurses?

Yes, I think so, and I'm not sure which would have come first. I suppose that attitude shift would have had to come first in order for me to see the change on the ground, in that, you know, things aren't taken over as soon as you walk in. In general, diabetes care seems to be much more focussed on raising awareness, education, and that magic word empowerment now. And I've seen that much more recently, obviously, in the DAFNE course, which I still get the impression is a very new thing, because in Birmingham I'd not heard of it. And I know it's sort of only trialled in pockets around the country, and I believe it's come over from Germany, so I've received, I suppose, the latest. But yes, definitely you can chart it with the three pregnancies and the three labours, quite apart from other times when I've been in hospital. There has been a shift, and I suppose within the fifteen years, of course, there's a new wave of doctors and nurses with a new set of medical education behind them.

- (16) And have you noticed differences in the National Health Service during the fifteen years you've had diabetes?

Yes, definitely have. As I say, at the beginning of that time when Rebecca was born, there was... you could see there was a new wave of diabetes specialist nurses moving in. And at first, I guess, I was a bit sceptical, because, you know, they did a six week course and got a certificate, and, at that time, the diabetic health visitor, who had had all the years of experience behind her, was invaluable. But I think during the fifteen years, I suppose, experience, and new technology, new training has come together more. And certainly now, you feel that there's a team of experts looking after you. And possibly - I don't know, five or seven years ago, sort of around the sort of '90s and onwards, '95, having had Grace, and then afterwards - there seemed to be more of a move from, well, what's called Diabetes UK now, but used to be called the British Diabetic Association would be telling you what care to expect. And so you, as a patient, had leaflets being given to you so that you knew what kind of things ought to be happening. And now, coming right up to date - I mean, I've always had free prescriptions - but in the early days people were fighting for the needle tips for on the - it's like a cartridge pen that I inject my insulin with. At the time you still had to pay for the disposable needle tips - those were being fought for to be on prescription, and they are. That sort of... And there's lots of new monitors with new technology. And now I've downloaded my software that I can look at my own graphs, and chart my bad control or improving control on my computer, if I'm interested to do so. But, in terms of people management, I see a podiatrist now. There was always a sort of a vague mention of "oh, you can see a chiropodist", but now it's much more a part of, you know, my annual review. And I get to see my podiatrist regularly, and she's put an innersole in my shoe to see what my feet are doing, by way of where I walk. And also within the

- (17) last two or three years, the retinal photography that's taking place, so that you have a photograph of your retina which you're able to keep and compare, so you're looking at any deterioration each year. Things like that

are... it's feeling like it's coming together. And in my own surgery, now, in Corbridge in Hexham, apart from the fact my own GP has a particular interest in diabetes, which is great, I'm able to really feel that there's a group of them that I can talk to for different things. But in addition, the DAFNE follow-up and the diabetes specialist nurses, I no longer feel that I'm talking to someone who just happens to have a course and a certificate on the wall. They are real experts, and they're working together. And just recently being asked, as a patient at the surgery, to be a patient representative on a little - I'm not sure what the correct term would be - a little diabetes working group within the surgery, so that, you know, they hear from me. It's much more moving across to listen, and I suppose it's consumerism in the National Health, which is good. I think, you know, with illnesses like diabetes, where they are managed by me, it's vital. I can't... you know, you can't treat your own cancer, but you can treat diabetes. And it's something that you have to live with long-term, and it seems pointless having to leave it in the hands of the medical people. But thankfully, technology has meant that within twenty seconds I know what my blood sugar is, and thankfully I don't have to pay the twenty odd pound per box of test strips, that quite a long time ago I probably would have had to.

- (18) And what do you think of more recent technological developments in the treatment of diabetes?

Well, I was recently just over in America, although I believe they're used over here, and that's personal insulin pumps, and a person was chatting to me about that. And I've been thinking through some of the things, whether I would actually choose them, and it seemed to me that the insulin pump, from what I know about it, I wouldn't particularly want to use it. I like to be in control personally of pumping the insulin in, rather than relying on a machine. But what I would like, which I believe is at the moment still quite too huge to wear on your wrist, but they are developing a sort of a - using an infrared light, I believe - a kind of a watch, which is a non-invasive means of blood monitoring. Because that's what you do a lot, because, as a diabetic, I'm often wondering "oh, I wonder what my blood sugar is now" if I'm going to take a journey, or... and you can end up with quite a lot of pin pricks in your fingers. And so a non-invasive blood monitoring machine would be wonderful, and to me, more wonderful than the idea of actually sort of having a transplant, although that's very much been in the news, of course, linked with sort of embryo testing and DNA, and things which are beyond my understanding. But to me, that's a major life-changing thing, which would be... I'd have to seriously think about whether it was worth it - something that would make my life a lot easier, but, and a lot more simply, would be able to glance down at my watch and see what my blood sugar was without having to do several pinpricks.

How long can you go in a day without thinking about being diabetic?

Hmmm, that's interesting. I've recently started working in an art gallery café

one day a week. And I dash out in a rush, I grab my breakfast - I always have my breakfast, I always have my injection and I've always done my blood test before. But, of course, once I'm in the shop and I've got the coffee machines bubbling and I'm ready, the first thing I always think about "well, I just need to check my blood sugar", because you're moving into a time of serving customers, starting work, where you can't just pop into the other room and relax and do a blood test when you need to. So, it doesn't go very long. And it's really "oh, it's approaching lunchtime", and so really, it's every mealtime, or at the start of something significant. What might not be significant for you, but something significant for me, is if I'm driving for... a little ten minute journey doesn't normally cause me any trouble, but if I'm driving into town, sort of half an hour, you do feel like "oh, am I okay?". And, of course, sometimes it gets to you before you think about it, because you have the hypo symptoms come on, which is great working in a coffee shop where they have nice cakes! And orange juice, of course.

- (19) Yes, I'm a person who keeps quite a regular diary. I think I actually started it not long before I had my first baby. But it's interesting looking through that, over - I think I've got about eight or nine volumes now. And I was scanning it through to try and remind me, and there are, of course, times when diabetes is going fine, and you're always sort of thinking about it on a day to day practical level "I'm going to eat, I've got to have my injection". Quite often, when you're sitting at the table, and you've just got the meal for three kids and your food is going cold, and you've got to stop and do your blood test and do your injection, and write it down if you're being a very good girl - writing it down doesn't always happen - you can think "oh", you know, "it would be nice just to be able to eat my food hot for once". But those are sort of the slight annoyances. And sometimes I describe it like having another baby. It's like a fourth child to me, I've often thought, because, you know, when you're going out with a child, you have to make sure you've got the nappy bag or the potty, or whatever stage they're at, and I can't do that. Being spontaneous is easier if you've got your insulin on you, which I always do. I always feel tied to a handbag because of it. I'm like "oh, if I could just go out without having to take my handbag with me". Then you think "well, I might need my blood test, you know, if I feel funny", and "what if I haven't got my orange juice?" and "what happens if I have a hypo?", and "if I got poorly and nobody would know who I was, and nobody would know I was diabetic if I had an accident". So, I do the sensible thing and always have it with me, and that's okay. But from time to time, reading in the journal, you find comments that you've just had enough. And in 1997, which I guess I'd been diabetic for about eight years - she was born in 1989 - in big letters I'd written "I AM FED UP OF DIABETES", huge letters, so it was very hard to miss as I was scanning through. I think that was probably the only time I've written it that big, but there are definitely times when, probably when other things are pressing in, and it's just another thing that you get

fed up of. But on the whole, as I say, it's not something that I've allowed to control me and my life, you know. I'm a dancer - you have to make adjustments and be

- (20) responsible. I am responsible, even though I'm not particularly wonderfully controlled. I never do anything that's irresponsible, and so you just feel occasionally "oh, I want to be a bit irresponsible and just not be diabetic for a day", and then you're kind of happy to come back to it. I'm quite... I don't know what the word is really. People say to me "oh, don't you get sick of being diabetic?" or "how do you feel about being diabetic?" and "four injections a day - isn't that terrible?". But, I... really, I always feel, "well, I'm alive", and, you know, I don't have cancer. I don't have terrible pain, which a lot of illness can give you. And so, if you had to choose something, it's not a terrible thing to have, because it actually makes you be quite sensible, and it's made nearly a responsible person of me! I'm quite sensible, really.

I was quite struck by your phrase "it's like having a fourth baby". Do you mean the fourth baby as you?

No, I actually mean the diabetes is like a fourth child. It's something you have to look after, like another child needs looking after. And it sort of is. It's always there, and in that way that, you know, at least you can get a babysitter and go out. You can't give someone your diabetes to look after and ignore it, and have a sort of night on the town without it. And so, in that way, I have been quite sensible, because if I am indulging in such a way, for instance, of course, at a wedding, I used to have a standard wedding dose of fourteen units - it was my wedding dose - whereas now I'm on a different regime, so it's a lot more flexible. So, you can indulge yourself and do the calculations, because I've been trained now and empowered to do so. But it is just something that you can't ever really forget, because there's so many circumstances in which you are reminded. I mean, for instance, employers, people that you're with for any length of time, it's sensible to let them know. It's sensible to check if you're going on a car journey. It's necessary that you've got your kit with you all the time, so just something simple and insignificant like not having to carry a bag around. It might seem like nothing to, you know, to yourself, who just can grab the keys and drive off. I have to think about my bag, and then I have to think about "well, will I be somewhere I can get food, otherwise I'll have to make sure I've got something with me?". So, it is. If I sat and thought about it for longer, I'm sure I could draw lots of parallels with it being like a baby. And it growing up, and, you know, you growing to understand it more. And at times - I have a teenager, as you'll have gathered. I've got... my first daughter's fifteen - at times we're having a head-to-head battle, and at times we're sitting quietly enjoying each others company. And yeah, I would say that diabetes is like that. Sometimes diabetes and I are in harmony and doing well, and other times I'm shouting at it "I want you to go away"!

- (21) You mentioned that you now feel more empowered, so can you tell me how

that came about?

Well, it was a friend called DAFNE. When my GP saw me - I think it was possibly the first appointment I had with him in the North East, as I say, in Corbridge in Northumberland - my HbA1c results, which should be between and six and seven percent, were over ten percent. I knew I'd come with not particularly good control, and he said, you know, "I think you need to do DAFNE". And so, I then discovered that DAFNE meant Dose Adjustment for Normal Eating, and it wasn't some poor lady that was to be done. And the subtitle of this course was very attractive to me, because it is "Like what you eat, eat what you like". I particularly like the second part of that, being someone who's never managed quite to lose the sweet tooth. So yes, it's new, and it's very intense. And as soon as he said it's a week long course, full-time, my heart sort of sank, like "well, I can't do that. I've got three children, one of whom is tiny" - she was two at the time, so it was last September in 2003. And, in fact, I went home and talked to my husband, and he just booked a week's holiday off work. And I don't... well, I know I couldn't have done it, because we were out of our home surroundings. You know, we'd only moved about six months previously from Birmingham to Newcastle, and not very near the grandparents. And so with my husband's work in Newcastle, we were just living a little bit out in Northumberland. And there are certain pockets of the National Health that were trialling DAFNE, and it had come over from Germany. And so I was referred to Hexham General Hospital, and one of the consultants there had been particularly keen on it, who I think had moved away, but there was thankfully a team of diabetes nurses and dieticians who had run - I think it was a fairly new thing to them - I think they possibly had run one or two of these courses already. And you needed to be a certain... I think if I'd have had an HbA1c that was twelve or more, they wouldn't have recommended it, because I think too drastic an improvement, too big a

(22) change too quickly, cannot be good. So, I was sent my letter and dutifully went along for a week.

Residential?

No, it wasn't actually residential, because I only lived about fifteen minutes away. We... part of it was that at lunchtime we were all marched across to the canteen. And we chose what we liked - anything we fancied - and we had the dietician and the diabetes nurse come and help us. We couldn't set fork or knife in until we had done our calculations, and then also worked out how much insulin that was going to require. The week, I can tell you a bit more detail about, but in general, I'm an arts person, and I've been a dance lecturer on the creative arts before coming up to Newcastle, and numbers are not particularly my thing. And I do remember that half way through this very intense week of counting carbohydrate, working out ratios for my own body at different times of day, producing overhead projector charts with what your blood sugar is before your meal, how much you're going to eat, how much insulin you're therefore going to take, how long the insulin that you're taking lasts in your body, whether



you'd had any exercise, whether you'd had any alcohol, and all these extenuating factors - by half way through the week, I said "if I don't go and look at something beautiful soon, I'm going to go mad", because it was very intense numbers. And I think some folk were struggling to keep up, because it was a lot of mental gymnastics, but it was absolutely worth it. It was the most life changing and empowering, specifically empowering thing. Because, at times, you're given the power to make decisions, but you're still left in a vague sort of place, where you're working on things that you're not particularly sure of. And the training we got, and the manual we got, and the diary that we got, and also the follow-up that continues, and, you know, the access just on the phone, and also follow-up meetings, all enable you to be very specific and feel like you really can make a difference. It is hard work, and the week following, it seemed to take me about half an hour before I could actually eat my food, but

(23) like anything, if you embrace it and practice it, it becomes easier.

It sounds dreadful to me. To have to make all these calculations sounds more of a burden than what was happening to you before. Can you compare and contrast?

It's funny, isn't it? I mean, having said I hate numbers - which I do, it's quite laborious - somehow the motivation to embrace all these numbers was there. I mean, at first, I suppose, you are a bit dubious of a new thing. Not that I'm big into diets, but I suppose it's like someone who's dieting being presented with the latest diet, thinking "oh, well that's not going to work". And, of course, for me, fifteen years a diabetic, and felt like I was kind of bumbling around with the wrong personality, and I was never going to be particularly good at it. Well, I saw the evidence within a short time, which is good, because I think I needed to see improvement within a short time, otherwise I'm the kind of person that would have given up. But I went in with an HbA1c of over ten - I think it was ten point two - in September, and then the little diary that's kept when I got to the end of that is approximately three months. And so then, at the beginning of the December when I sent off my own little capillary tube, 'cause we come out with a folder - again it's about empowerment, and you feel much more like you're in control, because you're deciding when you're putting your blood into the GP to get your HbA1c result - and you send off your diary and your little HbA1c record card, and then you get feedback. It's a little bit like handing in your homework. But, I think because the diabetes nurses that do it are so accessible and so lovely, they're so human - which again, you never strike up that kind of relationship with a consultant. They don't have the time. You don't spend, you know, five days of a week, nine to five, with the consultant - and so you get a lovely relationship. And so you don't mind sending your little book and having their comments, and Shirley has written, you know, fun comments in. And they're human and they understand, because they've spent a week with you, listening to you, seeing you trying to grapple with things. So yes, I'm in charge of sending off the blood result, and so, after the first three months,

(24) my HbA1c was seven point nine. And, as I say, the target is sort of six

to seven, and the target they'd set me was seven, 'cause it was a jump from ten. And I was just absolutely thrilled with that, but, as you said, it sounds horrendous. It was fairly horrendous. I had to bribe the children to give me like five minutes, at least, of silence. I'd put their tea on the table, and I'd say "right, now everyone's got to be quiet, 'cause I've got to count"! So, I would do my blood sugar and I would fill in what it was, and then I would have to open up my little reference book and work out the carbohydrate of what I was eating. Then I'd have to think what time of day was it, because my ratio of insulin in the morning was one-to-one minus one, which means I took one unit of insulin for every ten grams of carbohydrate, but then I had to take off one unit of the total, just because I didn't quite need exactly one to one. By the time it gets to lunchtime, I'm taking one and a half units to one – sorry, I said ten grams – yeah, that's right - to one exchange. I'm still talking about exchanges and I'm not supposed to. By lunchtime my ratio is one and a half to one, and by teatime my ratio is two to one. So, for instance, if I'm eating five portions, or fifty grams of carbohydrate, I'm actually doubling that in terms of the insulin I take - I'm taking ten units for five. So, depending on what time of day it was, then you do your maths and you work out the injection you're going to take, and also bearing in mind other factors like alcohol and exercise, all of which was gone into in great detail during the DAFNE course. There were about ten of us around a table in a little room. A real mixed bag actually, and you get to know people, because you share quite personal things. And, of course, for some, I mean in particularly some of the gentlemen, you get talking about impotence and Viagra, and, of course, we have a laugh. And then, at times, you know, you share peoples struggles as well, especially nine to five, at any one time, any of us could be actually having a hypo, and we're there struggling, trying to concentrate. And so there were jokes about who was eating the most custard creams. And someone, I remember, had a friend in the canteen, which was joked about,

- (25) supplying with extra custard creams. So, you build a relationship, and we did a variety of things. A lot of it was sitting and listening, a lot of it was sharing, and a lot of it was filling in and thinking. So, the whole week was taken up with nutrition, self monitoring, possibly some people slightly changed their insulin regime. I went onto a slightly different long-acting insulin, which has a level profile, rather than peaking around two in the morning. I'm now on a Lantus, which, when you inject it, it doesn't have a peak time. It sort of stays level for almost twenty-four hours - with me, it's not quite the full twenty-four, which I have to bear in mind. So, we discussed on a very individual basis, so we would each have our little diary blown up onto the overhead projector, and we would discuss "now, what did you take then?", and "why was your blood sugar that afterwards?", and "what would you have done if you'd have been Simon or Jenny?", or whoever it was. And in that way, you actually learn quite a few tips, and

by some people you feel encouraged, because you realise that other people have a lot more issues and problems. Some of them were quite down the road of long-term complications that can be apparent in diabetes. And, on the one hand, that, you know, you feel that you are lucky because you're not there, but on the other hand, it makes you aware that, you know, you could be there one day. Things like that are helpful as well, even though they're not sort of planned part of the timetable. So, you learn technological things about the actual insulin itself, much more than... you know, no-one has ever really taken time to explain to you how the insulin works, and how long, and when it's starting working and when it's gone out of your system. Because that, obviously if you're going to have, for some reason, a meal that's a lot earlier or a lot later, and your insulin taking is kind of combining, so you're getting two injections quite close together. Helpful things like that, that seem obvious that you should tell a diabetic, but no, no-one had ever told me anything about the medicine I was taking for those fifteen years, so. Also a lot about carbohydrate, and lots of games with plastic food

- (26) and pictures of meals. And then we brought our own packets in and the kind of things that we like to make at home, and we were able to ask very specific questions about that. We had special sessions on hypos and what to do. Members of our family came in for particular sessions and learned how to give the Glucagon injection, which, if you are comatose, there is a way of mixing a dry powder with a solution, and you can inject it then and there. We learnt about managing physical activity, which obviously for me, again, was very helpful. I'd never been able to have such specific guidelines about the different types of activity. You know, before it was just "oh, if you're going to do some exercise, eat a bit more pasta or take a bit less insulin", and that 'bit', the size of that bit, was never discussed, or. But also, you know, it's what type of exercise you're doing, and for how long, and what your blood sugar is when you're going into that, and how that's affected. 'Cause I would have, sometimes, a very high blood sugar after exercise that I never understood, until I'd been on DAFNE, and realised that if you haven't actually got any insulin floating around when you begin, that can be the result - that you're actually ending up with a high blood sugar afterwards, when you think exercise brings it down. So, there were quite a few myths and misunderstandings that got ironed out. One, which I think affected the whole group - we all thought that if we went into a diabetic coma because we had a low blood sugar, that was it - we were dead if no one saved us. But, in fact, it was explained - someone medical might take me to task on the way I describe this - but as far as I understand it, my own body would, after a while, kick in and create its own glucose which would bring me back around, providing, obviously, that I'd not had a huge dose of insulin or excessive alcohol or excessive exercise. But that in general terms, so that if my children... you know, they didn't need to feel like in a panic and responsible if they find me that they're the

only one that can save my life. I mean, that's just one small example, but things that you think you knew that just weren't true. So, we got a lot of individual personal opportunities, as well as general things like alcohol, eating out, healthy eating. In fact, I remember thinking "oh, they

- (27) haven't really gone on much at us about healthy eating", because you still expect the high fibre, low sugar, low fat thing. And, in fact, many of the things I'd been told about eating wholemeal and high fibre foods, say - well, back in Birmingham, probably about seven or so years ago, round about the middle of being a diabetic, there was big push, you know, government anyway, telling everyone they've got to eat like this, but high fibre, wholemeal. And I was led to believe it slowed down the action of the sugar in the blood and ta-da-da-da... And now, again, I understand that's not seen to be the case now, and that the reason for eating fibre is, yes, you'll feel fuller - it bulks up more in the stomach, but, in fact, in terms of effect on blood sugar, it doesn't make any difference. So, having forced my family to eat wholemeal spaghetti and pasta and bread for years, they're like "oh, why? You mean we could have been eating white starchy things all this time?"! So, yes, we just found out a great deal. Other things were annual reviews and screenings. There was a doctor available - if we wanted to speak to the doctor, he came in for a session - but, in fact, I found the nurses and the dieticians were... they are the people that help you live your life day-to-day. There were a few others sessions... yeah, very helpful if you're sick. Again, nothing vague, but specific rules about if you're feeling poorly, if you've got vomiting and diarrhoea, and actually given a chart as to how much of a percentage of your normal insulin to take; very helpful. And, as I say, there was... we evaluated the course, but also there were a lot of follow-up sessions as well that were available to us. It was an awful lot to take in, and I... you know, I'm quite used to taking in, you know, sitting in sort of lecture type situations and reading intensely and writing intensely. And some of the folk - well, coming from very rural sort of farming communities some of them - and you could see a kind of sort of a shell-shocked effect, and I know that a couple of the people have struggled to continue with it. One guy I spoke with, who... he worked on the roads,
- (28) he dug up roads for a living, and he was a real kind of man's man, and he went kickboxing. And there was no way he was going to carry a little black kit round, because it looked like a wussy handbag kind of thing. And so, I think some people find it hard to come into a new way of doing things. But the bottom line was, although it's frustrating for the health professionals who are trying to help and empower, the bottom line was you can tell that, you know, they respected the fact that it was his life. You know, they had educated, and, you know, we're all aware - we had a session on long-term implications - but, you know, they're the ones that are living it in the here and now, so they were prepared to, you know, back off and not be sort of tut-tut.

You're a graduate, but you're talking about percentages and ratios. I'd have thought this was beyond quite a few people.

Yeah, I think that's what I was sensing really. I did feel sorry. . . I mean, as I say, even though I'm a graduate, it is in the arts, and I'm much more a touchy-feely visual person than a numbers person. And it was clear that it was a struggle for some, and, as I say, the intensity, once we got about half way through, it was a struggle to concentrate, if you're used to farming as a lifestyle: very, very different. I suppose if you're running the business and you're having to do percentages and do the accounts, then you'd be in a great position. But there was a huge variety of people, so, I suppose, one way of possibly improving the course would be to think about the people groups that they have together, and the mode in which it's delivered. Maybe people would be able to take more of it on board if it was given in small doses. But the strength of the course is that over the week you are finding out - you're on a journey of discovery from Monday morning until Friday evening. You're actually finding out about your ratios, and it does need to be a continuous process. And I think that's why they know the importance of the follow-up, and there were things being repeated in these sessions, because they're aware

(29) that, you know, one hour talking about a certain aspect, in the midst of a whole week, will have got a bit buried. And so the follow-ups were very important - and, as I'm talking to you, I'm realising that I went to a couple, and I'm thinking "mmm, I wonder if I've just missed one recently", 'cause I had a letter of dates. But the people factor balanced out the number factor, definitely. It was hard work, but, you know, you built friendships. And there was one gentleman, in particular, who was already very partially sighted due to the diabetes, and retinopathy that he has as a result of that, and other people who were struggling with things like high blood pressure, and other things that may or may not have been to do with diabetes. And so it was great in many ways. So, although having sort of suggested that the course might be better sort of streamlining different groups together to deliver, in a way, you probably won't get, you know, one type of group. And even if you did, you would probably miss out on the sort of cross sharing and understanding that takes place. I think - I'm talking like a teacher now - but I think possibly different modes of delivery would help - a bit of variety - to take away the intensity, but it is, after all, a numbers game, whether we like it or not.

Do you feel it would have been equally good if it had been, say, once a week, rather than five days on the trot?

I think it would have been hard to get the things which needed the continuity, because, of course, the evening meal and the night-time insulin has implication on the next morning, and the next morning has implication on that lunchtime, and that lunchtime. . . And because, you know, as we've already said, you can't put a full stop, have a day off and then start again. It was because it was following on day after day - because you would discover something and you'd

need to discuss that - “okay, well, what’s my next step then?” - whereas you could have discussion. It’s possible that some of the input, the sort of

- (30) specialist sessions on alcohol or exercise, could have been spread out – so, possibly if you were going every morning, maybe having lunch, and then going off. It’s very difficult. I think it would be worth experimenting with though. I was just very grateful that I moved to an area and a sort of primary care trust where they actually had funding to do that, because I know it’s... I don’t know how much it’s being trialled across the country, but it’s only a sort of small number of pockets, I think.

Can you talk about how you feel empowered, now, in a typical day?

Yes. I need to be really honest with you and say that the initial improvement that I got has sort of bounced back slightly, so now I’m running at about eight percent, which is – actually, I think my last one was eight point four - still a huge improvement from the over ten. And so, I suppose, as with most things, there is an initial time when you’re really focussing. Day-to-day, now, I’m aware that I just need some little injections of reminders of the DAFNE programme, because the one thing that does slip with me is the diary. But, in fact, I don’t think they really... they don’t expect sort of five or six entries every day for every week. I’m empowered by the knowledge, which I am aware that you do need to remind yourself about - food-wise, and, from time to time, I can think I remember about a food, whereas I need to sort of dip into my little reference book of carbohydrate values. And I’m empowered because of the insulin types being much more user-friendly and much more flexible, and I feel like I’m... One of the big things that was introduced in DAFNE, that had never been discussed in fifteen years, was the idea of compensation doses. So, I was given a means, by which, if I do a blood test and I’m crazily high for whatever reason and I’m going into a meal, then I’m able to calculate a way of compensating and addressing my blood sugar, bringing it down to

- (31) what it should be, so that then I can calculate what I need for the meal I’m going to eat. And so you’re feeling like, if you do get into a bad situation, it doesn’t mean “oh, I can’t eat anything” - you’ve just got a way of putting that right day-to-day. And I personally don’t think I can hope to get through a week of perfect blood sugars. If I have a day of good blood sugars I’m pleased, because normally, at some point in the day, I’ll have a peak that, you know, I’ll go over ten, and - maybe not everyday, they’re not all too bad. But then, from time to time, you do have like a big peak, for whatever reason, and that’s when it’s really helpful, because you know what you can do about it. And what I should be doing more is using the reference book I was given. Of course, when you’ve got three kids, you know, it’s just time to set aside. And again, it’s that idea - bringing it back to being like a baby - because you can’t just look after a baby for... if you could spend like your Friday morning, one hour focussing on the diabetes, but you can’t do that - it’s a continual sort of thing. And that’s a bit frustrating, because there’s always lots of other things going on, and

you feel like “if I could just take some time out and revise my DAFNE for an hour, then...”. I mean, yes, I need to try and make time for that. The biggest difficulty is it’s just another thing to do, keeping writing it all down, but if you do write it all down, then that is very empowering. Because the whole idea is that you look back, and you see “oh, well that happened there and I did that, and that didn’t really work very well, so now I can try this instead”. I’ll get there, but I’m very pleased with it so far.

Can you describe a typical weekday in your life?

I’m not sure I have a typical day! Typically atypical. It would be a fairly frantic frenzied hour or so, everybody getting ready, getting rid of the... The two older ones walk out, they go to the school bus, and Paul goes off to work around eight o’clock, and then we have a frantic final getting ready and going to nursery. And that will be a grabbed couple of slices of toast, with the same injection and same breakfast happening for me most mornings. I have two breakfasts that I interchange. It will either be two slices of toast or it will be forty grams of sort of bran flakes with

- (32) fruit - fruit and fibre, and because I’m in that habit, that’s fairly easy. Lunchtime tends to be... the normal, I’ll be picking up Rachel at about eleven thirty, and sometimes we’ll stop in Hexham and have a sausage roll or something for lunch, and sometimes... most often I’ll be coming home. And she and I – again, I’m fairly... I don’t feel entrenched in it, but it just is sort of habit that I’ll have two slices of bread and a piece of fruit at lunchtime, so that’s fairly regular in terms of food and the time - I would be having it around twelve thirty. I think evening meals are the sort of biggest difference. The afternoon, well, we’ll have a play or go to the park, or we’ll, you know, do something with Rachel - that’ll be Rachel and I. And the children get back about four-ish, and then, I have to say - it’s possibly for any mother of three children - maybe if someone can cook it’s not so bad - it’s my worst time of the day, when everyone’s tired, and I’m tired, and they want food, and I don’t know what to cook. But we tend to eat, the three girls and I, because Paul comes in mostly after the time when everyone else is starving, so. And I’ll cook it frantically with lots of people wanting my attention. There’ll be piano practice going on, there’ll be drumming practice going on, there’ll be Rachel wanting to help me cook, and me trying to be patient with a three year old tipping things all over the place. And I’ll get it on the table, and that’ll be the first time I’ll have a bit of peace to think about the blood sugar. So, I’ll do the blood sugar and the injection, and then sorting out what the two older ones are doing by way of homework or going out. Rachel - story and bedtime regime is around eight o’clock. Thankfully, it’s funny how a move to a different place about a year and a half ago, we’re still in a mode of not being too busy charging out in the evenings, which has been interesting. As you get to know more people, you get busier doing more

things, but most of the time we're both pretty tired out from jobs and looking after children. And it's funny, I was well known on the DAFNE course for recommending red wine, because more evenings than not

- (33) I like to enjoy a glass of red wine some time in the evening, and, of course, it has a lowering effect on the blood sugar, and so that'd be something that we'd do. And I am typically the one that stays up to the dark hours, because I enjoy the time when the house has got quiet. And Paul - he works as a trainer for the BBC and has quite intense days - so he'll be... the house will go quiet around half past ten, and he'll go to sleep. And I'll be either writing my journal or in a book with my glass of red wine, and probably go to sleep far too late, which makes me tired in the morning, and there we go with our crazy regime again.

And are you doing any dance work?

Actually, I have just started to do that again; just a little bit. Having stopped the part-time lecturing in Birmingham and moved up, we were renting a house and then we were moving house, and our little daughter's been in hospital a couple of times - there's been various things that have taken time to settle - but what I did do on a Friday, I started work in a wonderful art café in Corbridge, just on the Friday. And that has obviously affected my insulin regime and the sort of routine of the home. But I have started, and have done a few days, of freelance dance education work in a first school. And it's quite exciting, because the high school in the partnership has just become a performing arts status school, and so the high school, working with two or three middle schools and then quite a lot of first schools, are all getting much more involved in the arts. And so, as Rachel gets older - she's just in nursery each morning, but next year she'll be in to reception class - hopefully I'll be expanding my horizons, again, into schools in Northumberland. And, of course, it has a great benefit on my general health and diabetes care. Although it needs managing, it means that I'm a lot fitter if I'm doing physical exercise. Because, being a person who's not very disciplined - I don't get up and go for a run like my husband does every morning, I don't ride the bike at the weekend like my husband does at the weekend - and so for me, work actually becomes quite a saving grace for my health, as well as relaxation and enjoyment. So, yes, I'm looking forward to building that

- (34) in, but only when it's not creating more stress than it's worth for the family and me.

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

I don't think it would be any different. I can say that now. Of course, I've reached that age of forty, which my GP tells me "within the next couple of months we ought to have a chat about such things as..." - I think he said about taking aspirin and making sure my blood doesn't get too thick. I think that's about - here I am speaking in ignorance, almost, because this is sort of moving into a new stage for me of being - I'm not going to say older - a more mature person with diabetes, and the things that that entails. Obviously I'm aware of



needing to care for your eyes and your feet, but in terms of things like blood pressure, which was a little bit up, which I think prompted the GP to talk about that, and also cholesterol levels, so we've got to go and have our "you have now reached forty chat". And it doesn't worry me. I mean, when you take four injections a day, if you have to take a tablet or something as well, it just fits into that regime. I must say that, you know, long-term - you obviously, you do hear and you do know that there can be some quite nasty results of some of the long-term complications of diabetes, and so you don't think about them very much. You sort of purposely put them out of your mind, but I suppose that things like that will be creeping towards me. But I'm pretty confident in the way my diabetes is managed, and so I'm not worrying about going blind, because I'm carefully monitored, and I'm told, you know, if things start to appear we can address it. Obviously I'm not a medical person and so I don't know all of the things that might happen or what the results might be, but I'm happy that, you know, we'll just address that when we get to it. And, in fact, the fact that I'm diabetic, although on occasions I've felt "oh, I'm diabetic", and so that's the kind of big heavy weight that's going to mess everything else up, that's just when I'm having a bad day. Really,

- (35) you see people getting older all around you, and they get complications of various kinds whether they're diabetic or not. And so, as I say, I don't think I'm any more fearful of the future because of being diabetic. But I think that's helped by the fact I know so much has happened in diabetic research and diabetic care. I'm feeling like there's lots of people on the case, whereas...

You've described very good medical care - the DAFNE course, the follow-up, the GPs post forty interview, which, I must say, I didn't have. Have you been aware, at all, of any of the strains and stresses on the National Health Service that we read about in the papers?

Do you know, I don't think I have? I think I've been fortunate. I haven't felt neglected - I haven't felt that it's tough being a diabetic. I mean, I think it's a real plus that we get free prescriptions, not just diabetes related prescriptions, and so I'm just trying to think whether financially diabetes has cost me anything. I've always had free... I think maybe the first testing kit I bought. Fifteen years ago I bought a very sort of, what was then, a very funky pen shaped blood monitoring device, and I think I paid sixty pounds for it. But, I mean, with the DAFNE course, monitors were given away free, and, I mean, they commonly are, because since I bought that first one, I have had two or three other monitors in between, and they've all been given me free. I have injector pens - two kinds of injector pen; I don't have to pay for any of that equipment. I suppose I do have to pay more for insurance, just thinking of that, in terms of car insurance and life insurance payments. You shop around, and I think because I'm female and over twenty five, that helps as well - and I don't drive cars with big flashy engines!

And personally, what keeps you going through all this?

Well, I remember when I was reading in my journal, when I was first diagnosed

- (36) I'd been a Christian for a few years. And my husband and I, we go to Church, and we pray, obviously we believe in God, and I'm certain that that... I mean, that's not something I had as a child growing up, and so, I suppose, I can contrast the not having that and, of course, not having a Dad around for a lot of the time as well. I was definitely able... my first reaction was to, you know, when I heard that I might be diabetic or whatever, was just to hand it all over. Because I have a sense of God, and being fathered, and that I'm made by God, it helps me very much to, I suppose, step back and not zone in on a sort of 'pity me'. And thankfully I'm not someone that has ever done the "Why me?" thing - "Why did this have to happen to me?", I think because I take a big view on things and I look around, rather than sort of zone in. You know, you see people struggle, you know hardship happens of various kinds, illness happens of various kinds, and I don't get knotted up about the whys. So, I've been able to cry to God and shout at God if I've felt like it, just like I cry to my husband and shout at my husband if I feel like it if I get in a bad mood about the whole diabetes thing, just as I would about any other occurrence, whether it's trying to buy a house or the car breaking down. I realise that there is more to life in the big sense than being healthy. I mean, I feel that I am healthy - I don't mean to suggest that I'm unhealthy - but having something, having an illness, having a disease, does not mean that you can't live a full and fulfilling life. And, of course, alongside... I suppose what I'm saying is that the whole spiritual aspect of life, because you have a spiritual outlook as well as a sort of just a physical or material limit to what you think life is about - that has helped me. And also, you know, my husband and my family, particularly my husband, has just been a huge support, so I've not had to go it alone in a practical way. So, I've had a sort of a spiritual stronghold, but I've had a practical support with my husband. And the girls, you know, they're only young, but, you know, they help in ways they can. And, of course, I've had good diabetic care. Thankfully, you know, I live now in the... I've lived in the twentieth and twenty-first century, and not, you know - when I think what my mum said about my dad's mum's mum, and I say "well, what happened to her?" and nobody sort of comments, and I said "well, she died young, I suppose" - and so, yeah, I'm thankful for technology, as well, at this time.