

5. Harriet Irvine

- (1) I was born in 1954 in London, England, and I was brought up in the centre of London, where I lived until I was thirty-three. My family background; a brother and a sister, a mother and father. . .

What did your father do?

My father was an economist and he travelled quite a bit. My mother did not have a job, I say, but she did textile designs, she did batik, a lot of working with fabric. I am the afterthought; my brother and sister are considerably older than I am. I think I was a mistake at the end of the line, and found it was a very nice jolly childhood.

What kind of education did you have?

I went to a grammar school, Godolphin and Latimer, on the west side of London. We lived near Marble Arch, quite near Hyde Park.

Did you know of anybody who'd ever had diabetes before you were diagnosed yourself?

Oh yes. There was actually one girl in my primary school who had diabetes, and once I had been diagnosed, my mother got together with her mother and we met up. But that wasn't very successful socially, I must say. I think she felt that I was infringing on her territory!

Can you remember what impression you had of diabetes from her or the media or anywhere else before you had it yourself?

The only thing that I remember is that she had Dextrosol in a flat pack. She used to pull them out, and I thought they were very odd and they didn't look very interesting at all, and that's probably about all I knew about. I didn't know anything about her not being allowed to eat things or, in fact I didn't know that she did injections, so all that did come as a shock later on. Otherwise no, I didn't know anybody at all who had diabetes, that I was aware of anyway.

So let's come to the time of your own diagnosis, how did it come about?

I was at school, and I suppose it was a sort of school nurse person that rang my mother and said that, I think rang her, or maybe my mother was there, and said that I should be taken to the doctor because I was losing weight. And I just remember it being an awful time, in between every lesson could I get a . . .

- (2) have a drink of water, and anyway, my mother took me to the GP and the GP tested my urine there, and that evening we went straight into Great Ormond Street. So it all happened very, very quickly. What I remember mostly about the pre-diagnosis is just the thirst, and it was very difficult to work. I would be plotting my life around when I could next have a glass of water, and that was interesting!

What year was that?

Well that was 1967, when I was twelve. And I was taken to Great Ormond Street, where I stayed for six weeks, and it seemed to be very, very slow, everything that happened in there, but that was where I had a lot of training, well grounded in how to look after myself and how to be independent. I wasn't allowed to leave until I could do my own injections and count out portions and test my own urine, and all of those things. They were quite strict.

Can you talk me through the details then of each thing, first of all injections, how were you taught to do those?

Well I was taught with an orange, which I think was very classic, and then I remember there wasn't much choice after that, it was just straight into the leg and that was... I remember the sister of the ward who was excellent, talking me through it then, and I think I took a very long time before the first one happened, but then I don't know, I don't remember a lot more after that. I assume I did it and then went on doing it!

What were the syringes like?

Huge, they were enormous. They were metal and glass and, compared to what we use nowadays, incredibly heavy. The needles were metal, and in hospital we did get a new one each time I think, but at home there was lots of boiling. I had got past the stage where people had their needles sharpened for them, so a bit more modern then. I remember the testing the urine, which was all done in test tubes

- (3) with bubbling, actually I don't know what it was made of, but I know it was poisonous and you had to be very careful how you handled it, dropping it into the urine with a certain number of drops of urine, number of drops of water, and then this pill that went in and fizzed. And if it was blue it was excellent, but usually it went kind of green, and then orange if you had been deeply wicked or unwell! I do think we were taught that it was very wicked to stray from the diet and not to keep to absolutely the precise times every day, so that was quite daunting at first, and I think my mother found that very difficult when I came home and said "I can only eat this, I can only eat that, I can't eat anything bigger than that and I have to eat now", whereas before we had eaten probably later in the evening, and it changed things at home I think.

Can you remember the details of the diet that you were given?

Hen's egg sized potatoes. Yes, well I can remember bread with crusts on, bread with crusts off, thicker bread, thinner bread. One portion with the crusts cut off, and if it was thicker bread it was two portions, and the hen's egg sized potatoes were very annoying because potatoes are not hen's egg sized. I used to remember things, well yes, two hundred and fifty mls of milk with one Weetabix, and those kinds of things.

Would they have been mls then or would they have been...?

I don't know, I'm sure it was two hundred and fifty something though, a glass. You're quite right, it probably wasn't mls.

(4) What was it like to be in hospital for six weeks?

When I think back on it, as I said earlier, it was very slow, but I was never without entertainment or people. It's a great hospital, Great Ormond Street. I must admit, I still have strong feelings for it. I think I was always entertained. I remember sitting spending hours filling in the bits about some poor child in an iron lung and horrendous things like that. From my point of view, it was the full training that I got. I remember the day they made me experience a hypo. They'd given me an injection and no food, so that was quite interesting.

So a deliberate hypo?

Yes, so I knew what it would feel like. I can remember that, I can remember precisely what I was wearing as well, it was very odd, but I mean I think it was quite useful.

What was it like?

Like a kind of out-of-body experience. I could see myself on the bed getting very hot and sweaty, and I was wearing a blue dress with white spots, and the nurses would come in and talk me through about what was happening, and presumably they must have left it up to a certain point before they then gave me some food. I mean, I don't think anything dangerous was about to happen or anything, and then I think I must have just started to feel a bit low. But I hadn't experienced that before, so that was quite useful.

In what ways was it useful?

Well the theory being that when I left, I would then recognise it myself. I think it was useful in that respect. What else do I remember? I remember that the majority of the other children on the ward were much sicker than I was, which was quite difficult, and that was a huge eye-opener all round really. A lot of them that had been there a long time knew a lot more about diabetes than I ever did: "Oh, yes, you're diabetic", before I knew that I was diabetic. I don't actually remember a lot about my parents, and I think... I know they came in a lot.

(5) How did your parents handle things when you got home?

Well, I think I very much was in control. I think that is what happened, as I suppose I came out quite... I was the one that had been taught everything and the empowered person. I think my mother felt uncomfortable because she didn't feel that she could perhaps look after me as she felt she ought to be. I think things changed slightly once I got back into the swing of it and went back to school, and I think school found it very difficult to deal with. They'd never had anybody else who was diabetic and I was told "I couldn't eat this", and asked if I was all right the whole time. And I think I definitely, in fact I'm sure I played on that and was very often quite sick, "couldn't go to school, it was just

so awful”, which wasn’t a good thing, and I found it, I think that’s probably the first kind of taste of any discrimination, but looking back on it, you think, well, how much did I influence that by making more of it than necessary?

What sort of discrimination?

Well mostly from, well in hindsight the school then said that they didn’t think that it was a good place for me to be if I was unwell, and perhaps I should move on, so I did. I was then, I was about fifteen then, and in fact I was sent away to a Quaker school for a year, and that was very interesting. It was

- (6) a direct grant school called St Christopher’s in Letchworth, and it was a Quaker school, and I think my parents thought that it would give me a chance to become independent again and to re-establish some kind of good feeling about being at school, which had dissipated somewhat I think over the couple of years previous, and it was a good place. It was a very interesting place, and they just didn’t really seem to take much notice of whether I had diabetes. There was the ‘matron’ person who looked after all my kit and everything, and I used to go to her and do my jabs, but she didn’t really take much notice. I mean, she obviously did, but it was not evident, and I think it did help a lot. And I did my O Levels there, and then said I didn’t want to go back there and wanted to come back to my friends in London, and I went to a further education college then to do my A Levels. And in fact, it was probably a good thing, probably the right time to send someone off, when they’re fifteen, to go to boarding school, as well. And the other good thing about it was the fantastic food. It was all vegetarian, and I remember the food being excellent, and nobody came out and said “you’re not allowed to eat that”, and it was very different.

But you presumably still made your own strict diet?

Well yes, presumably I did. I mean, I went to hospital and nobody told me off, I don’t think, at that point. When I came back to London, I remember I was still with Great Ormond Street, and I think I was about seventeen, so Lower Sixth equivalent, and I had an abscess in my tooth and went back to Great Ormond Street because I was vomiting all over the place, in a terrible state, and I went back for about a week or two while they dealt with the tooth. And I remember that being quite significant because I was on the cusp of being moved on, and there was a lot of talk about me moving on and I’d grown out of this hospital and all of that, and I remember that being quite sad. I went on to the Middlesex after that, which I don’t remember, I remember very little indeed.

The sadness of leaving Great Ormond Street suggests that you’d had quite a close and constant relationship with it.

Yes, well yes, very much so.

How often did you go there?

I don’t know, but I still somewhere have my books that I used to fill in all my

tests in, sometimes quite hurriedly making them up just before going to the clinic. And by the time I was sixteen, I went by myself. I must have gone a minimum of every six months, or more even, and I can remember precisely where the clinics were and I can tell you the name of a couple of doctors, but they were always very nice, yes. Very protective, I think.

(7) Did you see the same staff over the years?

I remember there was a doctor, or maybe he was Professor, Newnes, and I did see him a lot, and the people from the ward would be at the clinic as well, so yes, you would always see the same kind of people, which was very comforting I think, yes.

When you went on to the further education college, was anyone responsible for helping you with your diabetes then?

No, I was. I don't even think they probably knew, I think I'd gone into a bit of denial at that point. No, I was very much on my own, and wanted to be, I think I definitely wanted to be very independent at that point. And that was all coincided with having this abscess, which meant I did get very ill. I had to go in, and that was the kind of moving on. So after that, as I said, I was at the Middlesex, and I can't remember anything, very, very little about it.

Was it difficult having such a strict regime as a teenager?

Yes it was, it was at the beginning, but I have always tried to manage my diabetes. In fact that was something that was instilled in me at that point was that, you know, it's your diabetes, you have got to deal with it, and therefore you need to be independent, you need to be able to do all these things yourself, otherwise you'll never get on with your life. That might have been quite new at that moment, but it was something that was really hammered into me, and it maybe came from my parents as well. So I think what happened was that then, I just did manage it, and I think even now, I tend to always eat about the same every day, and it has influenced probably my life and it's become quite methodical. And if something happens and I do miss a meal now, it does put me out, yes, so I think it has influenced me, but I think what I did was to move to live round it rather than let it control my life, and that might be my kind of personality and it might be because of the way I was, you know, that time that I had there.

(8) Before we move on to your leaving further education, can we backtrack a bit and talk about your parents, more about you parents' reaction to diabetes?

Well I do remember coming home from Great Ormond Street after the six weeks, and they were, I think, suffering from extreme guilt and worrying about what they had done to initiate this problem. And I think they worked round it and worked out that it wasn't actually their fault. And they'd started to look into the family to see if anybody had had diabetes, and the only person they'd discovered was in my father's father's family, he was one of twelve. There was somebody

called little Amy who apparently died of a wasting disease, and that was the only link that they had, but I think she became possibly more important than she had been before. I think they found it very difficult to cope with and there wasn't very much support for them in those days, I don't think, at all.

What did you do after the further education college?

I went to take a Diploma in Fine and Decorative Arts, which was a vocational diploma, because I wanted to work in museums, which I did do. As regards the diabetes at this time, it doesn't figure very much, I can't think of anything very much about it. I had a normal social life, long term boyfriends. I suspect I did hide it a bit, quite a lot. Anyway, I did the diploma and went on to work. I got a job in the bookshop at the British Museum, where I met my current husband, and then I then went to work at the Tate, where I was for nine years.

Did your colleagues know you had diabetes?

Yes, they did. They were very good at the Tate, because it's quite useful working in large institutions where you get time off to go to hospital appointments and things like that, but it never seemed to figure very highly until I had - I'm not quite sure of the dates, I've talked about this with my husband, I think it was the early '80s - I had a stomach bug or I'd eaten something, and I ended up in intensive care at St Stephen's Hospital. I had been absolutely fine at lunch time, gone home and started vomiting and ended up there, and apparently everything got very dangerous, and they couldn't find veins to put drips into and all sorts of things. And that was an interesting escapade, because they said, "yes there had been an infection but I hadn't noticed anything", and they put me through a bit of retraining actually and changed my insulins.

- (9) As far as I was concerned it had been due to something I had eaten, and the hospital were not absolutely sure, they thought I had an infection, but nobody knew precisely why I'd ended up in this terrible situation, because I had not been aware of my blood sugars roaring high, or anything previous to that, so I was convinced it was food poisoning. They were interested and wanted to, I think they probably felt that I'd been on the same regime too long and perhaps it was time I had a bit of a change, which is not at all unhealthy, and they put me onto Insulatard, I think it's Insulatard, this is my problem I can't actually remember, but they did change my insulins, and it was around '81 or '82. That was an interesting hospital, I think that was where I first... They introduced lots of other things as well, talking to me about diet... anyway, that hospital doesn't exist any more, I think they'd just started up their diabetes clinic and were trying to move forward in that area. But it might be because I had this very, very intensive relationship while I was in intensive care, that after that they were quite protective and looked after me, made sure I was all right.

What sort of changes did they suggest to your diet?

I'm not quite sure whether this is something that I initiated or that they had,

because this is actually a slightly cloudy area, because at some point I will have moved on to different insulins. And I had been on the same cloudy and clear ever since I had left Great Ormond Street, and it would have been an old Isophane and whatever the clear one was called, soluble, and I think I was moved onto this Insulatard, which has more of a background, longer coverage and there's less peaks and troughs. And this was the time when they were talking to me, and I think this is when I got much more interested in diabetes and why things were happening and how things were happening, so it was another new area of education that I found fascinating really. And I think maybe they were saying "well maybe you had had the infection and you hadn't realised

- (10) it, and therefore we think you should change your insulins so you can start becoming more sensitised", maybe.

How often were you having injections in this new regime?

Well this was another area that I have been talking to my husband about, because we couldn't remember when I changed. I think that I changed in about '85, when I was pregnant, to four injections a day, but that was fantastic freedom suddenly then to go to four injections a day. And previous to that we had moved and I'd started at King's. Aren't we fickle, us diabetics? Terrible, trotting all over hospitals, all over London, and King's was fantastic, as they have a very good diabetes clinic there, and I got pregnant soon after I started there and they were just amazing, and we both felt very, very well looked after and everything went very well with the diabetes. I think it was at the beginning of that that I was put onto four injections a day, so one basal and three, one for each meal.

What year was that?

I would have got pregnant in '85 because he was born in '86, June.

So we'd better backtrack then to take you from working at the Tate and talk about how you got married and so on.

All right, okay, we married in '78, and I'd just started at the Tate and he was at the British Museum, and we met and married in six weeks, twenty six years tomorrow!

How did your husband cope with you being diabetic?

He copes very well, most of the time he doesn't take any notice, but he's always the one who is there when there's a disaster, so he's very good at handling the Glucagon. In fact, for the first few years there were no problems, it wasn't until the St Stephen's incident, and after that I think I took more interest in my blood glucose levels. I suspect I had been a bit lax before. Moving into the pregnancy, where we tried to maintain

- (11) six, a blood glucose level of six the whole time - that was interesting, it was a very interesting exercise for me. I found it quite difficult at first, and then worked out how to do it.

How?

I think a lot of it had to do with the kind of food we ate, so I'm certainly somebody who tends to eat complex carbohydrates for breakfast, otherwise I don't get through the morning, and things like that, so I've learnt things like that. That was a big learning time, and I knew that if I didn't eat the right amount or the right kinds of carbohydrate that my blood sugars would drop very fast. It was quite easy to stop them going high, but it was far more difficult to stop the drop, and with the hormones rushing around it was quite difficult, so I did have a couple of incidents where my husband was ringing ambulances in the night when I went very low, and that was when he was given Glucagon should that happen again. The pregnancy went very smoothly and I was very well looked after, and King's was excellent, and I was given a date to go in to be induced and went in to be induced, and I tried absolutely everything, every drug possible. We played poker for hours and nothing happened, and that was I think twenty four hours. And then, because it was our local hospital, we knew quite a lot of people there, so my husband went off with one of the nurses to the pub, and at that point, he was a good friend of ours I add hastily, the monitor on the baby's head registered that his heartbeat had dropped so we had mad panic, and he was hauled out the pub and I was hauled off down to have a caesarean. And it was after that, after I'd had Dan and everything, that the team who looked after us while we were pregnant came in and said they were very disappointed that I'd had a caesarean, because I had been one of the first to be allowed to go to forty weeks. Because I had had such a smooth pregnancy and everything had been fine they wanted to see whether it would work, and I don't think it was anything to do with the diabetes or the dates, it was

- (12) Dan really, he still stays in bed the whole time so he wasn't going to come out on time, so that was very interesting. Very good care in hospital and it was a pleasant experience, it was great, they were fantastic.

How did you cope coming out of hospital with a baby and diabetes?

I can only assume that the team there must have given lots of advice when I was in hospital. I remember getting a lot of encouragement to breastfeed and how to handle that, so to eat and drink while feeding. They also put my insulins right down, because, of course, they went right up during the pregnancy, so my requirements went right down and I was told to keep it a bit higher rather than running low, because that would be very difficult I think. That seemed to work out okay. I was given some very good advice and encouraged to do all those things, and the health visitor afterwards seemed to, well he's fine! A large strapping male, tall and all those other things, and still sleeping, and he, it seemed to go very well really. After six months I went back to work, that was okay, and when he was about fourteen months I found another job and went part-time, because in those days you went back to work and you got your job back, but you couldn't go part-time like you can nowadays. So I did, I found a part-time job where I worked for a company that bought art for large corporations, and that was interesting. I worked two long days and a short day



and had two days off, and that worked very well, so that was good.

- (13) Right, the part-time job I continued until '87, when my father and brother both died within three months of each other, and my husband was held up outside our front door by somebody with a gun. The consequence was the house went on the market very quickly and we moved to Oxford, mostly to get away from London, but also to be within commuting distance for my husband, and somewhere my mother could come to as well, so moved to Oxford and the John Radcliffe. At this point, I think I requested to go on to human insulin, to try human insulin, at the JR here. I do remember various things, like going to the JR and being put on a Friday afternoon appointment, which meant you went there with everybody else in the whole of Oxfordshire who had diabetes. And I remember going with my son, who was not very old, and looking at all these people going "I can't cope with this", so I went up to somebody and said "my son..." and got pushed in before everybody else in the queue, and I went to my GP and said "that's it, you're to find me another clinic", and that is how I ended up with David Matthews. I don't know if that's of interest at this point, but I got put on a special consultant's list. I threatened to leave my GP because the other GP had a diabetes clinic within the practice, and I said "I'll even go to the other one", and she said "no, no, no. I'll get you into a Monday morning clinic", and it was fantastic. You used to go at nine o'clock on a Monday morning, be down in half an hour, then off to work or back to normal life. None of this sitting around all Friday afternoon.

And where was this?

The Friday afternoon one was up at the John Radcliffe and the Monday morning one was down at the Radcliffe Infirmary, yes. I think there were lots of changes happening all over, and the clinic from John Radcliffe was moving down to the Radcliffe Infirmary as well, but it happened to be a good coincidence, and I thought I did very well out of that. And at this moment, I think I asked to go onto human insulin to see what it was like. It had been in the papers a lot and I'd been on porcine before, and in fact I found it very difficult and it made me extremely sensitive, too sensitive, for me to be able to deal with it and a child, and, you know, normal running around, so I went back to porcine. And it's interesting, because since then I'm now on human insulin, so I think they have refined them a bit.

Did David Matthews agree that your problems were caused by your change to human insulin?

Do you know, I don't know if I was talking to him or not. Yes, I think definitely they would have done, because I don't remember any conflict at all. I think I just said "this isn't right for me, I've got to go back", and I think when human insulin was first developed a lot of people found it very difficult, and the animal insulins were being withdrawn and there was a big...

Remind me what year we're talking about.

Well, this is the problem, I think it was late '80s roughly.

(14) Tell me about your second pregnancy.

Well I became pregnant in 1989, and was at the clinic at the JR because they had a pre-pregnancy, I think, counselling service which I went to, even though I was pregnant, and I was then transferred to the Silver Star people who look after diabetics who are pregnant, which I found very slightly odd, because I felt it should have probably have been the normal diabetes specialists. I have a major problem because I can't remember the name of the consultant. Whenever you wanted to see him, he'd gone to see skating, and he lived quite close by in Headington actually and I've forgotten his name. But I found them very, not as advanced in their thought as King's, and we're talking four years later. And I found that they were more restricted in their thinking than I was actually prepared for, I think, and I found it quite difficult, because the diabetes clinic was quite open minded, but this area I found...

Where was this Silver Star service based?

Oh, it's up at the JR. The Silver Star was part of the maternity services at the John Radcliffe Hospital, and they tended to look after anybody who had a potential problem or had problems in pregnancy. What happened at King's was that you still went to see the diabetes consultants, and the people who looked after people who were pregnant, the doctors who dealt with that, would be there as well as advisors, but the primary care would be given by the diabetes consultants. At the JR it seemed to be the other way round. The obstetricians were the ones that looked after the people with diabetes and didn't have as much knowledge as the diabetes specialists, and that was what I found very difficult, and a rather, well a very different way of thinking about it, and I found it rather old fashioned and restricted. The pregnancy was very different. I knew she was a girl, because I think hormonally it was far more difficult to keep at that level as it had been with the first pregnancy.

(15) Yes, hormonally I... Yes that's right, in the first pregnancy it was quite easy to keep to a level of six, blood sugars at level six, and trying the same, with a daughter, with the second pregnancy, I found that it was far more difficult. And I think my theory is that it's because of the hormones, but that can't be proven, I'm sure, but I knew she would be a girl because I think there were many more female hormones than in the previous pregnancy. We went through the pregnancy reasonably well. I would have very frightening lows, where I'd be sitting there in the middle of supper and suddenly just fall off my chair and end up on the floor, and I think my husband found it very difficult indeed. And our son was taught by neighbours to put notices in the window if he found me slumped on the floor and things, and he was three and a half at that point and was very aware, and made very aware, that things could go wrong. And it was far more difficult, that pregnancy, in that respect. Then, when we got further down the line towards the end of the pregnancy, the Silver Star people,

the obstetricians, started saying “well you know you’ll have to be induced at thirty eight weeks”, and I had a big argument with them and said “I went to forty weeks with my son and still ended up with a caesarean”, and they would not budge. They said “no, that’s it”, and I’m sure they were absolutely right, they had had some problems and some babies dying at that point and that was their protocol, so I chose to go for a caesarean, an elective caesarean. I wasn’t going to even try with an induction or anything. So that was that, which was a bit sad really. I understood their reasons but I couldn’t understand really why they weren’t willing to discuss it, or to take it a bit, you know, perhaps even another week.

(16) Can you describe the birth?

The caesarean went very well, except afterwards I had to, or a day later I went off to have a blood transfusion, because I can only assume I lost a lot of blood in the caesarean. Our daughter was very small, just over five pounds, I think that’s right, and with very baggy skin. She obviously needed to put on some weight, and could have done with at least another two weeks! But otherwise she was fit, she was fine, she was fit. She didn’t need to stay in the special care baby unit at all, though there was discussion about it, she was just borderline weight for that, but in fact she didn’t need to be. And that was fine, and good care afterwards, but also I think from what I’d learnt with my first pregnancy certainly I carried, you know, afterwards, the breastfeeding and eating, making sure eating every time I fed and all of that, I continued to do after our daughter was born as well.

What happened after the birth of your daughter?

Well, in the October of the year that she was born, 1990, I opened a business with my mother, which we ran for four years, finished just before the end of the last recession finished, but that’s another story. And then I moved on to work in Oxford colleges, and I now work at Oxford Brookes University. I was working in an Oxford college doing fundraising and I was asked to move to another Oxford college, tempted by more money and nearer the bus stop, which I started in June ’99. And in September 1999 our daughter developed diabetes and she was in hospital, not for very long, but the place I was working were not keen to give me time off to look after her and to go and visit her in hospital, and so I left there, and that I very much feel was discrimination. Even though I’d only been there for three months, they thought “oh here is someone with a child with diabetes, they’re going to need lots of time off” and not keen on that, so I left.

How old was your daughter when she developed diabetes?

Nine, she was nine. We could move on to talking about that. That was an horrendous shock. I had always been told there was a three percent chance of a mother passing on diabetes and a much larger chance of the father passing on, and I remember my first appointment at my clinic after she had been diagnosed, with some poor doctor I’d never met, and I went in and screamed and shouted at him as if it was all his fault that our daughter had developed diabetes. But he did, despite me being so horrible to him, wonderfully

- (17) arrange for us to go and see a geneticist, which we did, and that was actually very, very interesting. He was in no way going to commit himself to anything, but he did tell us how complex diabetes is genetically and how very difficult it is to determine who may and who may not... He told us about various studies going on, he told us a lot about the progress that is being made and actually it was an absolutely fascinating... He gave us long time, he gave us about an hour and a half, and then wrote a full letter afterwards telling us the chances that our son had of producing children with diabetes and what our daughter's chances were, and why he thought that Grace, that's the daughter, developed diabetes, and that was because her father's uncle had type one diabetes, his mother has type two diabetes. So in fact, there were possibly more genetic factors coming through from her father's side than my side, but the combination has ended up with her being diabetic. We can go back to her care when she was initially diagnosed. She was diagnosed at the GP with a urine test, and the GP then rang us at home and said "I've organised for you to go straight down to A&E and straight through", which of course they all say that, and you get to A&E and five hours later... That was terrible. Never go to a GP at five o'clock on a Friday night and then go to A&E, but I'll know that in future. I knew at that point that she had diabetes, and she didn't know and was unaware and didn't know why she was there, and that actually was very difficult because I didn't want to say anything without some medical backup or somebody there to, in a way, protect me in the future from her completely hating me. The weekend was interesting because they were closing wards left, right and centre. We went in Friday night, I stayed with her Friday and Saturday night.

Which hospital?

John Radcliffe, the children's ward, level four I think, and

- (18) yes, they were closing a ward on the Sunday, and the consultant there, who is a very excellent lady, came and spoke to me and took the history and did all those things, and when she discovered that I was diabetic as well she said "well as you know what's going on, I think you can take her home because we need her bed". And that was the most devastating, awful thing anybody ever said to me, however... so I went off and wept down the corridor, came back, and by that time actually the diabetes nurse had arrived, thank goodness, because she was fantastic, and without her there was no way we could have moved ahead at all. But I really did think that we were just going to be left, "here's your syringe, off you go, bye bye, try this dose and we'll see you on Monday". That was more or less it while we close the wards, which was absolutely terrifying. And she was right, I did know what was going on, I had a much better idea than, there were two other children who were diagnosed that weekend, and I had a much better idea going on, and of the three, yes, I was the less risk choice, or Grace was a less risk choice with better support around her, or more

knowledgeable support, but it was, that was really unpleasant. However, we did get very, very good support, but comparing her diagnosis and her time in hospital with mine is, it's worlds apart. And we were asked a lot, because apparently there is a lot of thinking in Scandinavia apparently, they are thinking of children going back in for a couple of weeks and having intensive training, and they are rethinking it over here. The problem is resources, as we all know, I think.

What do you think should have happened?

I think she should have had about a week in hospital really, just to have had some training, because now there's videos, there are CD-Roms, there are computer games, all sorts of things that are available to train, to give them more information. I mean, in fact Grace is, she's a very bright kid and she's very knowledgeable, but she's only going to take a certain amount on board, especially if somebody else will carry it for her, and that is... I don't know, it was very difficult at first. The nurse used to come for every injection, which was fine, and then she stopped coming because lots of children... there was only one diabetes nurse and there were maybe, it is a particular time when clusters seem to be diagnosed, I think it's in the early Autumn and this was when it was, September, and she had three or four newly diagnosed ones all over Oxfordshire, and she just couldn't come for every single injection, so we were left, which was fine, we knew what we were doing, and the nurse would come whenever she could, and after two or three weeks Grace went back to school. The school have been absolutely brilliant, absolutely fantastic from the beginning. I will say that because so completely different to my experience, and she's flourishing there. This year actually, having not having ever had any diabetics, there are now three in the school, and as we know it is on the increase, but it's evident throughout.

(19) Can you spell out how your daughter's experience at school was different from your experience at school?

I think first of all they were very, very ready to take on the situation, that they really might not have known much about, and I think that is a different attitude. So there was no discrimination, it was very open, very "oh yes, I'm sure this will be fine and we can deal with this". The diabetes specialist nurses have been fantastic and will go in whenever the school asks. I spend a lot of time talking to each new year teacher and developing a relationship if necessary, but I am saying that actually Grace is the one with diabetes, she is the one that's knowledgeable and you must talk to her, and they do, they do talk to her. And there is a fantastic school nurse who is tremendously pragmatic and also very clued up, and it's worked out very well, and she's doing very well. I do think that that's common across most schools now, I mean I certainly hope it is. I don't think this one is peculiar, and I think that is a major, major, major difference from my time.

What other differences have you noticed in your daughter's experience of diabetes?

The other one is that, well, the attitude in my day was we'll take her into hospital

for six weeks and she will be taught, and when she leaves she will be able to walk out and look after herself, whereas, you know, two nights in hospital, which were very unpleasant really. It was very, very obvious about lack of resources, they were closing wards, and the mixture with very, very young and also tremendously sick children I think is not healthy. I can understand why they don't want to keep children in for a long time. So she came home. We had support from the diabetes nurse, who is excellent, but, as I said, was only one covering the whole of Oxfordshire at that time. After two or three weeks where we were able to give her her injection, Grace suddenly started to rebel and that was very difficult, and I had to use her brother to come in and help me, which he found very difficult. Eventually, after much talking to the diabetes nurse, the nurse came round and said "I think Grace wants to try herself", so she did, from then on she did her own injections. Once she'd done the first one it was absolutely fine,

- (20) and she then felt empowered and in control, and that is the big difference, I think, between my experiences and hers was that I was given that, although I think it probably wasn't thought of in that way, but that empowerment that Grace has now that she didn't have at the beginning, that once she'd started to do her own injection she felt much better. Other differences have been, I think there's a lot more information about diabetes out there. There has been a lot of support, I mean I have to admit that I have demanded it as well because Grace also has adolescent epilepsy, or we hope it's adolescent epilepsy. She tends to seize when she has hypos and they are absolutely terrifying, and so she's also on drugs to try and control that. We have played around with her insulin, she has been on all sorts of different regimes, and they have been very supportive. And I suppose the other thing that is a huge advancement is that I left Great Ormond Street on a certain dose, which I sat on probably throughout my whole adolescence, and my hormones must have been raging and my blood sugars must have been all over the place, as has happened with hers. From that point of view, the knowledge nowadays is far greater and we are able to fine tune her regime to a point where she can do whatever she likes, eat whatever she likes. She's the kind of normal person, normal adolescent, who will sit in front of the television most of the time then suddenly go out and swim sixty lengths, which as you can imagine, from the point of view of managing diabetes, is very difficult, so we do have some problems, and she is getting much better at anticipating them and controlling them herself, but it's taking time, whereas I think I was pushed out into being in control very quickly. It's very different, we can't say which is better and which is worse I think.

Has she received further training to fine tune her dosage?

No, except last time we went to the clinic, we discussed the fact that she likes to go and do sixty, or sometimes more, lengths and how she should deal with that, and she is on Lantus with Lispro, so very fast acting, so she can use that and manipulate the way she handles her life, though she's not yet at a point to use

that to its fullest advantage, but I think she'll get there, she will, yes.

- (21) So what about your own experience of diabetes as your daughter has been growing up?

Well the one interesting thing that I've found is that her new regime is really very, very adaptable, and I asked to be changed to that last year, which I was, so I'm on basal Lantus, which is a twenty four hour one, and NovoRapid. I did ask to go onto Lispro, because Lispro is much quicker, but was told that Novo was the one that they recommended, and I wonder if that's because they're the people that sponsored their building, but I do hope not, we're not cynical. I think I have found that my diabetes is much easier to handle. I always used to use the other insulins as I do this, so if I didn't eat lunch then I didn't eat lunch and didn't do an injection before, but though it's easier now on the faster acting ones. Previously it would have had a knock on effect later in the day, but now if something happens and I'm in a meeting and don't eat lunch, it is much easier to handle with this Lantus and NovoRapid, I really do like that control. My HbA1cs are very good at the moment!

You talked about hiding your diabetes when you were younger, has that continued?

I've found that now, when you apply for jobs and things, it is asked for, "do you have a hidden disability?", and no, I'm much better about it now, though it doesn't come up very often. I am much better about it because I find that people, especially in employment, I think we're seen as a plus, part of the quota, so from that point of view I have been declaring it much more, and I think before that, there were certain times when I probably didn't talk about it, but I mean I always have with driving licences and those kind of things or insurance or something like that. But otherwise, it's part of my life, so in a way I don't talk about it very much. It's not, thank goodness, I don't have major problems and I hope that I don't, and in which case I don't need to talk about it the whole time, it's just that's it.

And what about your daughter, is she quite public about it?

- (22) She has been very public and used to show off doing her injections in front of everybody, which I have to admit I found very uncomfortable at first. I think I've always been taught to, or felt that it should be hidden. But I now think that it's fantastic she does that, and I remember going to a meeting at Brookes where I work, and there was another girl there who is diabetic who just got her stuff out in the middle of the table, and she must be about twenty five, so of that similar... and I thought "ooh", and then said "oh, well I'm diabetic", but of course I whiz off to the loo to do mine. I think that people are far more open and it is far less, it's not so hidden, it's not something to feel ashamed of or to be, you know, just kind of dealt with.

Has your experience of diabetes been affected by the fact there is more in the

media about diabetes?

Yes. I think the big thing at the moment is that people, if I say I'm diabetic, people say "well you're not overweight", and a lot of people think of diabetes as the type two, and there's not enough information about type one, I don't think. I do think they're very different and I do think people get those, well they're completely different, they might be called the same thing but they're not, and they're handled differently, managed differently. Yes, I think it has not been particularly positive for type one diabetics, really, to have this much information about type two in the media. And it's very negative, the type two things, very, you know, "you don't take enough exercise, you're too overweight, you're going to get diabetes and you're altogether very wicked", and I think that's awful for them, and it's also has not necessarily a good knock-on effect towards people with type one diabetes.

- (23) Are there any differences in the way your daughter relates to the medical profession compared with the way you've related to the medical profession?

I think she's been taught by me, I hope she is, that because of our conditions, that we are in a position to be able to use the NHS to our advantage, and I think usually we can. I mean, every now and again we come across a problem that doesn't figure highly with diabetes as well, but usually it does mean that we can get more out of the NHS than possibly someone who doesn't have diabetes. Being thirteen, I think she still relates through me, I tend to do a lot of the talking. I do try and ask her to talk as well, and she has asked when she is able to go by herself, so I think that she will be able to relate hopefully. I think she does relate very easily but it does tend to happen through me, and having thought about this, perhaps I ought to be standing back a bit more now, and I hope that she will, you know, make sure that she uses it and does well out of it as well.

Why were you so devastated when your daughter was diagnosed with diabetes? Why did you burst into tears?

I suppose it's absolutely fine that I have it and I deal with it and I get on with my life, and I'm not going to say let it interfere with my life, but to impose that on somebody else is difficult, it's very difficult, and it is hard to watch her and see how it does affect her. I think she handles it very well. I think she has no idea of there being any discrimination, or previously that there would, because her friends just take it on board and don't take any notice. She sits there checking her blood, squirting blood all over the place, and nobody says anything, and needles come out. Generally, I think the way she handles her diabetes is different to the way I handled it at first, but my feelings about her having it are actually very difficult to talk about, and I don't know how to, it's very... Yes, you're absolutely right, I have handled diabetes absolutely fine, but no, it's no good to have anybody else close have it.

- (24) Do you have any message from your own experience for anyone who is diagnosed with diabetes?



Yes, I think that I've now had diabetes for a frighteningly long time and that things have got better, they have really significantly improved, especially recently, and I think that very soon it will not be, this will be history, and people will not be having injections and it will be dealt with completely differently, and hopefully nobody will have it. I think the other thing is that maybe I have come across as being rather glib about my diabetes, but I do think that I just deal with it as brushing teeth, and that's just the way that I have dealt with it and not everybody can deal with it in the same way.

- (25) In 1967, or maybe '68, I was told that I wouldn't be able to have any children, but I have two, and they're both rather nice actually, so don't believe everything you're told when you are first diagnosed. I think it's far less of a solitary existence nowadays, being a diabetic. It's far more socially acceptable to do your injection in front of people, and my daughter goes away on trips with other diabetics. And when I was first diagnosed, I did feel like I was the only person in the world who had diabetes, and that I should hide it and it wasn't anything to be particularly proud of, which I think it is now. I think my daughter is not ashamed of being diabetic.