

16. Gillian

(1) Tell me about your family background.

Well, I was born in Pangbourne in Berkshire. My parents had very different backgrounds. My mother came from a wealthy background - her father had been a jeweller and sadly died at the age of thirty-three with cancer of the bladder, so she never knew him - and was brought up by a step father, who was an artist, and who then went into the civil service. And so they had a reasonably comfortable background. My father has a very working class background; big family, from Southend. I think it's probably true to say that he excelled their expectations, in the sense that he took a job after he'd done national service with the John Lewis Partnership, and was pushed quite hard and went into management. When I was four we were living in a council house, and my father won a thousand pounds on the Pools, the Vernons I think it was then, and we moved into a house that had fairly recently been built, in a village on the outskirts of Reading called Woodley, which then grew and grew and grew, and doesn't look anything like it did in that time. And my father stayed with the John Lewis Partnership, and retired some fifteen years ago. And my mother was a school secretary from... I think probably I was eight or nine when she took on that job. So, I guess a pretty solid middle class background. I certainly grew up thinking I was middle class, rather annoyingly I think, in the sense that I was very aware of that, and some of my friends at school had more working class backgrounds. And I'm ashamed to think back on that really, because I thought I was a cut above.

Tell me about your schooling.

I went to a very nice infant school, and then moved over to the junior school, part of the same school, and did reasonably well. Did my Eleven Plus, and I am told that they had to push me through so that I passed, and not go to the secondary modern and to go to the grammar school. But I went to the grammar school, where I was extremely unhappy for a very long time because I was very badly bullied. I was an underachiever; I remember almost nothing about five years, so I can't help you on that I'm afraid. Didn't do very well on my GCSEs, but was picked up by a man I shall be eternally grateful to, who was the deputy head of the sixth form college, and who said that he thought I could A Levels. And two other teachers backed him, and I flew from then. Did very well in the subjects I liked, and got good A Levels and went to Warwick University.

What subject did you do?

At Warwick University - English and American Literature. Not what I'd chosen to do actually; I wanted to do English and Theatre, but I went through clearing, not having been your ideal university candidate.

(2) I went to Warwick University, which I enjoyed enormously, although I spent more time in Durham because my boyfriend was there. I didn't make the most of it academically, but enjoyed the time, apart from a couple

of incidents, which I think did mar it fairly significantly. One was that towards the end of my time, I was developing clinical depression, and I really was very unwell with it for some time, and was put on drugs that I think would probably be considered inappropriate now; largely tranquilisers rather than uppers, in any sense. And that spoilt things a little for me. And I also picked up a very unpleasant virus, which I will never forget, because I have never looked or felt so ill, and it was very non specific. The doctor at the time called it a respiratory virus, so my respiratory system wasn't in any sense affected by it, so I'm to this day mystified by that diagnosis, but it was very memorable. And I have wondered, since, whether that may have been the mystery trigger to the diabetes that was to come later.

You hadn't got any diabetes in your family then?

I was the first diabetic in my family that we know of, but, of course, we don't know anything about my mother's father's side of the family, so there could have been, I would say, an early child death, as it would have been in those days; not recorded or not known about. So that could be, although my mother is enormously anxious to stress that there isn't any diabetes in her family. My father, likewise, we don't know... we haven't been able to track anybody down. My mother was absolutely convinced that one of my grandfather's sisters died of a wasting disease. We've been unable, entirely unable, to track down the sister who died, and we think possibly, I'm afraid, that she made that up; not consciously, but she needed it not to be her family. Since I was diagnosed, my cousin became diabetic during pregnancy, and didn't lose it afterwards and is insulin dependant, and her sister had gestational diabetes and no longer has it, but obviously it's seen as a risk for type 2 in later years. But that's it. We don't have that obvious link with anyone anywhere.

What did you do after you left university?

I didn't know what on earth I was going to do actually, so I got offered a job by a friend's friend's father, who was a director of Rothmans, and he was setting up - setting his wife up in a little cottage in Wales with a Post Office attached, and they were going to run the Post Office together when he retired. But she was making a beautiful garden that she wanted people to visit, so they wanted someone to run the Post Office for them. And it was a beautiful little village called Cwmbach in South Wales, and I went there for a year and loved it. It was a farming community, beautiful scenery; absolutely perfect environment, I thought, for me, but, of course, no opportunities career-wise afterwards. And I remember going to some dreadful sales interview in Swansea or something, in the faint hope I could stay in the area, and not having the faintest clue what I was doing or saying, and not getting the job and having to return home to Reading. And then to a job in London as a trainee journalist, through connections I'm sad to say; a little bit of nepotism there. And I started on a trade journal, which was deadily dull, but gave me solid training.

(3) How did your diagnosis of diabetes come about?

It was rather strange really, because I had no idea that I was becoming ill, other than the lingering depression, which I was still fighting. I went to holiday in Greece, and I look back on the pictures, and I was so incredibly thin it doesn't seem possible that somebody hadn't marched me to the doctor's. But since I had accepted that I was simply nice and thin, I suppose it wouldn't be fair to expect anyone else to pick up on it. But I was at work one day, and one of the secretaries said to me "you're horribly, horribly thin now, you know, Jill?". And I was absolutely terrified, because I realised it was true and that I'd been in some sort of denial about it. And, of course, thinness, with my lack of medical knowledge, but the little that I had, made me think leukaemia or cancer, basically. And it wasn't long after that - again a very singular event - I was thirsty at work, and I rushed out across to the corner shop and bought myself the worst thing, of course, in retrospect I realise I possibly could have, which was a can of Coke, downed it in one, and was still feeling desperately thirsty, and thought there was something wrong about... definitely something wrong. And I wasn't completely ignorant of diabetes, although it was not me that made the connection, because, the connection we had was that my mother's stepfather developed diabetes type 2 when he was about seventy five, so we knew a little bit about some of the classic symptoms. I still hadn't made the connection, but I rang my mother and said "I don't know what's the matter with me. Everyone says I'm thin, and I keep drinking all the time", because by then I realised, of course, I was drinking a lot more, and it sort of crept up on me. And I went to see my GP, who wasn't the most sympathetic GP, and pooh-poohed it a little, but nevertheless sent off a sample to the hospital, and was very unimpressed with the result. I think - I can't remember how they measured things exactly. The figure ten sticks in my mind - I was only ten, my blood sugar was only ten; I think that was what it was, which was not desperately significant, but anyway he'd send me to the Whittington Hospital. And I got to the Whittington Hospital and saw a very nice man, who said, very quickly put me through a glucose tolerance test, which is a deeply unpleasant experience - drinking a lot of sticky material and having blood tests done every half an hour, I think it probably was, and confirmed that I did indeed have diabetes. And I'm not quite sure how they could judge this, but they said I was about a fortnight off a coma, and it would have been very dangerous indeed. And I was taken in to hospital the next day - that was September 1979 -

- (4) and I stayed in for - unbelievably, looking back on it now - for nearly a fortnight, where I was taught to inject an orange, and had my condition explained to me to some extent, and given some laughable dietary advice. It really was quite absurd the advice I was given, again in retrospect, but knowledge of diabetes then obviously was more limited.

What was the advice you were given?

Well, there were all sorts of things that people would laugh about now. And I actually finally got released from hospital, because I'd had enough of being in

hospital for ten days, despite a strikingly handsome young doctor who did make me feel perhaps it was quite nice to be in hospital for a while, and they wouldn't let me have marmalade on my toast. This was the final day and I kicked up terribly. I was very fed up of being in hospital by then and I didn't accept that I couldn't have a sliver. I mean, I think someone had said I could have a sliver and someone else said "no, you can't have even a sliver of marmalade on your toast". And, well, I made a fuss about it and I found myself at home the next day, funnily enough, clutching something that my family will never forget, which was some handwritten dietary notes on diet, which were almost illegible, totally unhelpful, and left me feeling very much like you feel when you come out of hospital with your baby; completely unable to cope, not knowing what on earth to do without support around you. And having a salad that evening, thinking it was sensible, and realising that I'd put salad cream on it, and ringing the hospital almost in tears, desperate because I'd put salad cream on my salad, and I thought I'd have done myself some terrible damage. So actually, my understanding of my condition was pretty minimal.

Can you remember any more about the diet in those handwritten notes?

I think it was basically to avoid sugar, and really to avoid it - not a question of understanding about refined sugars and unrefined sugars, anything like that, just avoid sugar. And that carbohydrate was important, and I think I had a very vague idea that one digestive biscuit equalled ten grams of carbohydrate, but how that related to anything else then I can't truthfully remember. And the business of the notes, actually, is really rather down to my family, who to this day will say "can you believe those ridiculous notes that you were sent out of hospital with?". To me, it's all rather vague, because I guess I was coming to terms in my own time with my condition, so some of those details are more vivid for my family than they are for me.

What other education and training did you get in hospital?

Not a great deal! And not very impressive, I fear, if you look at it from a modern day perspective. I was put into a hypoglycaemic state so I would recognise it another time, and I don't think - that was a deliberate event, and I don't remember it being particularly traumatic, just vaguely unpleasant, as indeed hypoglycaemia continues to be. So, I think I probably did then know what I'd feel like, and that was good. But I also went into a hypoglycaemic state some point later, and I had to have glucose intravenously, and it went under my skin instead of into a vein. And that's one of the most painful experiences I've ever had, next to child birth I think, and a very apologetic doctor afterwards. And I was obviously more severely hypoglycaemic then, because that really, really was unpleasant. Apart from that and injecting into oranges, there was no blood sugars.

- (5) Blood sugar monitoring equipment didn't exist then, or if it existed it wasn't something that was generally available, but obviously the hospital had it and regularly took my blood sugars. To be honest, I can't remember

the significance of the numbers or being taught very much about that, and I certainly didn't leave hospital with a machine anyway. It really was all going to be guesswork, and it was guesswork for a long time until my parents bought me a machine, which I remember was enormous and cost sixty pounds. And my friends laughed because it was a birthday present, and said were they going to get me an iron lung next time!

You can't remember which birthday that was?

I think it might have been a couple of birthdays later. The question was that they were available, but at a cost, and it wasn't something that the hospital expected most people would be able to afford to buy. I guess that's the reason.

So how did they expect you to keep track of your blood sugars?

Well that's - looking back again - that's quite incredible, because the only way you could keep track of them was the blood test they took when you went into hospital for your checkups, and that, of course, only told you what your blood sugar was at any given moment. And it used to be very funny, because there'd be a group of diabetics - we didn't know each other - outside the clinic saying "no, bet you haven't eaten a cake today... you should have seen my diet today - lovely rice, some vegetables", and, of course, not what any of us were eating most of the time. And we thought we were hoodwinking the doctors, and indeed to some extent we were, because they didn't have anything else. Apart from, of course... no that's not true is it? We had the urine tests - I've missed out something vital; that's what we had. We were taught how to pee on a stick, recognise the change in colour - orange definitely meant we had too much sugar, blue was a negative and was fantastic if you could achieve that. And we did keep a record of those. We took those with us, but again, as everyone knows now, that doesn't give an accurate indication of your control. It takes a certain while to go through your system, so certainly if you peed on a stick and it was negative, it didn't mean that your blood sugar wasn't a hundred and fifty as you sat there at that time. So in terms of control, it really wasn't very adequate.

Where was this clinic?

It was at the Whittington Hospital, which is a pretty grim old building, but with a fantastic consultant, whose name escapes me - and it should come back to me, because he is the nephew of someone very famous in the diabetic world. It may come back to me - and he was very, very kind and very nice to me. And I think they did very, very well, given the time and given that the hospital was not particularly modern - I compare it with Addenbrookes.

(6) I look back in complete horror. There was rubbish piled up outside, it was smelly and dirty, and very basic in many ways.

So what did they do wonderfully?

They were very kind. I think, you know, I couldn't possibly comment on how adequate they were medically - I'm sure they were as good as the time allowed,

but I remember the kindness, and I remember my own GP at the time. I remember I'd developed a cough, and I went in because I thought I perhaps had lung cancer, and he said "it's really not very likely that you're going to be diagnosed with diabetes and lung cancer within a year, Jill". And he was kind as well, he was supportive, and he did say - there's certain words that ring through from past times - and he said "you do know you're going to spend a lot of your life in clinics, don't you? So you'd better get used to that", but not unkindly.

What were your reactions to the diagnosis?

Well, I think probably my doctor would say perhaps that I've been in denial all my life, on the basis that I haven't ever really reacted to it. My parents, my family generally, thought - well, it sounds very big headed - thought I was amazing, I was fantastic, because I didn't let it affect me. I didn't feel any grief about loss of health and I felt very determined just to carry on, and that could have been denial or that could have been positive thinking and getting on with my life. People would have a very different interpretation, I suspect, of my approach. But I certainly went on doing a number of things that I shouldn't have done, which included drinking a great deal of beer. And I think I was pretty careful with my diet, but as a vegetarian and aware of health issues generally, I did try quite hard with my diet anyway, so that wasn't a major problem for me. So overall, I can't remember being traumatised by the diagnosis. I think life continued very much as it was. I didn't feel injecting was a desperately appalling thing. I was determined to think it was like cleaning my teeth - you know, clean my teeth twice a day, stick a needle in twice a day. It wasn't as if it hurt after all, although looking back on the equipment that I had at the time, that again is pretty laughable. I probably ought to mention that my sort of training on that was pretty minimal.

- (7) As I mentioned before, I'd been shown how to inject into an orange, though quite how that was supposed to help I can't imagine - it didn't really. But I was also told how to look after this hideous huge glass syringe with a very menacing large needle on the end of it, and basically it involved boiling it in water in a standard aluminium saucepan, which I did regularly, but whether I did it as often as I was told. I can't remember how many times I was told to do it, I really can't remember. But I think there were two things, and I'm serious about both of them, although one of them is going to sound slightly frivolous. I was madly in love with my doctor at the hospital. By the end of the fortnight, you know, I wanted to impress him, I wanted to be seen to cope, so that really was an issue. And the second thing is that, of course, I was very relieved because I didn't have cancer, I wasn't going to die. I had something that I could go on living with, and so, perhaps, that was a lot to do with why I appeared to cope quite well.

How did other people react?

I can't remember many people understanding enough about it. I think most people said "how awful, you've got to inject yourself. I'd be terrified. I'd die

rather than inject myself twice a day”, and that really is about it. My family certainly - I’d left home obviously by then - never became very involved, and never to this day really understand the disease, and I’ve certainly felt some resentment about that. I remember going home, and I seem to have to remind everyone every time that I had to be told twenty minutes before the food was going to be served, because I needed twenty minutes or half an hour, and they always seemed to be surprised and not to have remembered it. And it seemed so important to me, I couldn’t quite understand why other people couldn’t have grasped those very basic things. I suspect my brother probably understands diabetes very well - I expect he read every book ever written on it actually, but he’s very laid back and not desperately sort of hands on. But he’s very, very supportive, so he is there. But my parents, I think, perhaps they really didn’t want to know.

How did manage your diabetes at work?

I don’t think it impacted at work at all to be honest, because I was on two injections a day, of animal insulin then, of course, and so I’d had my injection in the morning before I came to work and had my injection after I went home. And I guess the people around me had limited interest, and then began to just accept it, as people do. That was part of my life and that was it. And it wasn’t until a little later that I met - a couple of years later - that I met the father of my children, whose brother was diabetic, that I had the chance to talk to someone about diabetes and what it meant, and someone who understood and knew something about it, after all, most things are quite boring to other people after a short while.

(8) So how did your diabetes progress in your twenties?

My suspicion is that I was a lot luckier than a lot of people, quite honestly, because it really didn’t impact very dramatically on my life until certain things went wrong, and they’re very memorable. The first was - I was on Rapitard at the time - and I was at a boyfriend’s house and I was coming home. And I hailed a taxi and I got into it, and I couldn’t remember who I was or where I lived. And I somehow, as we... I don’t know, the taxi driver must have been enormously sympathetic. He must have thought he had a mad woman in the back. But I sort of remembered bits of the address, and yes, I definitely lived in Camden, I got that far, and then I can remember vaguely recognising that I was in the right place, this was Camden Road. And somehow I got home, and realised I was hypoglycaemic and ate, and was okay. It wasn’t long after that that my flatmate came in to find me working my way through my phonebook ringing friends and telling them to “fuck off”, and fortunately realised that wasn’t normal behaviour and rang a doctor. And I was taken into hospital, where I stayed for several days, and my insulin was changed, and I can’t remember, but it was still animal insulin. And that wasn’t very pleasant, because it reminded me that it could be pretty serious and I did have to look after myself a bit. And I also had had over that time, in no particular order, a number of very unpleasant revelations/comments from other people. One of the worst things was picking

up a New Scientist, and I'd really quite like to track it down again, because I can't quite believe I could have understood properly, but it said that a diabetic from diagnosis had about twenty years, and that made me forty two. And I was at work, and I rang my brother up and sobbed down the phone "I've only got twenty years". And that's when, I suppose, I realised that I could actually die from it - it was going to stop life being exactly as it would have been if I hadn't had it, and that was very, very grim indeed. But as I've said before, I have an enormously supportive brother, who pointed out all sorts of things, like that that was taking into account people who abused their diabetes, who hadn't recognised that they'd had it for years, all sorts

- (9) of things, people who die from other things but happen to have been diabetic, and put it in proportion. That was... he was great - he really, really did help me, but since I'm mentioning it, you'll know that it was a very grim moment. And the other thing, I suppose, was - I can't promise this was very early on - but I certainly was seen by a nurse to be pricking my fingers fairly centrally, and she said "you mustn't do that", very angrily "mustn't do that. Why are you doing there, it's supposed to be on the side of your fingers?". So I said "well, I always do it there", and she said "well, you mustn't do it there. You've got to do it on the side because you'll lose the feeling in your fingers, and then when you go blind you won't be able to read Braille". And that was very unpleasant, but almost laughable actually - sort of unpleasant but laughable - you know, get this nurse off the ward, get her sacked and do something about it. Never did, of course; never even complained. And the other life changing, and probably the most life changing thing in the whole story of my diabetes, was me saying quite casually to the consultant one day - I was twenty six, so yes, I do know when it was - "should I think about having children?", because it was something I knew I'd very much wanted to do. You know "is my diabetes going to stop me getting pregnant or make it more difficult, and I'm getting on a bit now anyway, aren't I?". And he said very casually indeed "yes, I think, you know, if you're going to want to have children, you should think about it now, because after all, you've got to consider whether you're going to see them grow up", and that was shattering. I just remember walking away. I had no support, no backup, no anything. No one saying "but, you know, don't panic about it. That sounds like a dreadful thing to say, but doesn't everyone have to think about the future and be, you know, realistic? And isn't that why women don't have children when they're fifty?", and all those sorts of things that might have made me feel a little bit better about it. But I went home thinking "well, have children now, because they won't have a mother when they're twenty unless I do it now". Not a good moment.

Were you in a relationship in which you could have children?

I was in a relationship where I very much would like to have children, but certainly my partner of the time didn't see the relationship in those terms.



- (10) And I think you could say that I was also playing the field. He wasn't making any commitment to me, and I had a number of other boyfriends - none of them serious enough from my point of view to want to marry or have children with, so time was getting on, and I was beginning to feel quite anxious about it. And the decision that I was going to be a single parent came upon me fairly suddenly, I think. I introduced it fairly gently to my mother and father. My mother was very accepting, my father looked stony-faced and disappeared behind the newspaper, and my brother was very supportive and said "whatever you do, I'll always stick by you" basically, not quite so sentimentally, but more or less that was the message and I knew it was true. So I started to think a little more closely about exactly how I was going to achieve motherhood, and shortly after that broke up with my preferred choice as a father. And looking back on that, life just seems very ironic, because he was the person I mentioned who had joined the dreaded and boring trade magazine and who had a brother with diabetes. And that is what drew us together, that the conversations we had about that and him being sympathetic and supportive actually caused that relationship to blossom. So again, even that's sort of down to diabetes - some of the life changes that happened, in a very strange sort of way. But he wasn't father or husband material - he always said that, and it was true, but I was not interested in anyone else being a father. And, of course, I also had to make a decision about whether it would be moral to just go ahead and have a child anyway. And as time went on, and we had a fairly major split, I started to wonder about sperm banks quite seriously, and one night stands, and thinking how horribly sordid that seemed when you could love someone. And even if they didn't want you and possibly not even the children either, at least there was something there that was special from the beginning that would make it all right, I suppose. And he was aware that I wanted children very badly. And at that time I did an interview about planning to be a single parent. And we split up briefly during the time when his father died, and after that we got back, and the first thing I did was play the tape where I said quite clearly that my immediate
- (11) plans were to be a single mother. And I asked him what he thought, and he said he thought it was a very good interview and he never made any other comment. And he never took any responsibility for contraception and nor did I, and was highly thrilled to discover I was pregnant. By that time, I also knew it was important to look after myself. I'd got my diabetes under the most incredibly good control. By this time we had much smaller machines, much more accurate machines, it was all a lot less messy, and anyway, it was worth it - I'd do anything. I was really... you know, when I fell pregnant, I knew that I'd done it in the best circumstances. I was healthy, I wasn't drinking, I wasn't smoking. And I told the father, and said how jolly happy I was and off he could trot. He'd done me an enormous favour and I really, really didn't want anything from him, and

he found that he really, really couldn't leave, if you can not leave when you haven't been together, if you see what I mean, but anyway. So I went through pregnancy under the care of Dr Yudkin, who'd been my consultant throughout my time in London and my twenties, and he saw me through safely. I gave birth to Tom naturally - very thrilled about that, because one of my concerns was meeting, in the pregnancy clinic, a girl who had been diabetic rather longer than me, but she'd also been anorexic, and she wasn't going to be allowed to give birth naturally - and this is very grim - because they felt, if she strained, that she might burst the vessels behind her eyes, which were very vulnerable; obviously one of the complications of diabetes and she hadn't looked after herself very well. And I was appalled that a) that the reality of not looking after diabetes having lead to something like that, and b) the thought that, you know, I might not be able to do it myself naturally, because I'd like to have a go at that. But I kept enormously good control. They were very pleased with me. They said they hadn't seen anyone with such low HbA1cs who hadn't spent most of their life conked out on the floor. And I was induced, but gave birth to a very healthy bouncing eight pound five ounces boy, and very thrilled I was too.

In what year?

1987.

(12) So what was your life like after that?

Well, by that time, various work changes had taken place. I'd left the deadly dull trade journal, been briefly freelance in a similar sort of field, ie deadly dull, and then being asked, or headhunted I like to think, to launch a rival deadly dull magazine, and did that, and was a features editor on it for a number of years. And this was still in London and leading up to my decision to have a child. And when I finally decided that really was going to happen, I left that job as well, and worked freelance for probably about a year, up until I had Tom. I spent a year in London freelancing in fairly grim circumstances really, because I went back to work two weeks after I had Tom, which was madness, and had a nanny in in the flat looking after him while I beavered away at the computer. And with no expectations of the father, who clearly had been utterly over the moon the moment he was with me during the birth and as soon as he saw Tom, and yet had no great desire, I think, to become a family man. And eventually, on a walk one day, was very moody, and I asked "what's the matter?", and he said "I suppose we ought to think about getting a house together, for Tom's sake", rather like saying, you know, wouldn't it be nice to have his teeth pulled out very slowly and painfully. And I didn't feel really that I valued myself so little that I'd take that as an offer, and made the decision to... again, my brother being very influential had suggested I came to Cambridge. He said "well, you've got a little boy", and he was living in a nice village with brilliant schools, and he said, you know, "why don't you just move down here?". And I had a number of very close friends, who didn't want me to do it, in London, but also friends

who weren't going to be closely involved with someone with a young child, you know, for very good reasons; no criticism of that at all. So, I decided to move. I also thought "sod you" to the father really. And moved to a lovely village with a beautiful primary school next door, and was coping fairly well. And the diabetes had been fairly well behaved. While I was breastfeeding I had one incident, and the only one I've had in my entire life, actually, as a diabetic, and I know I've been incredibly lucky as far as that goes. I

(13) had been breastfeeding heavily, and had gone to bed and woke up to find that the baby was crying, and there was something wrong with me and I had to get help. And I had a flatmate, and I was trying to open the door and my hand wouldn't connect with the door handle, and it was desperately frightening. And I screamed for help, and my friend came in and called the doctor, who lived next door - a very nice woman - and it took me about five hours to recover, and I had a desperate headache. And I'd been so frightened by it, and actually that's an interesting point. I hadn't any knowledge of how bad hypoglycaemia could be, and those sort of things that it could do in the night if you went low enough, slowly enough. So I rang the hospital, and the doctor said "yes, that's absolutely typical. It's rather like having a stroke in terms of its effects, and it would take five hours to recover, and it won't have done you any damage". And I was a little bit more careful about eating a bit more when I was breastfeeding after that. So that really brings me up to being in Comberton with a child of one, and a new hospital - the very modern, up-to-the-minute Addenbrookes - new clinic, new people, and a new GP, all of which was very good news for me.

And what year is this?

1988, which is the year that I switched - I believe it was when I became a patient at Addenbrookes - switched from animal insulin to human insulin, and I was very relieved to do that. And this probably sounds very foolish, but I have to say that briefly, when I was told that I had diabetes and I was going to have animal insulin, as a very strict vegetarian I actually flirted with the idea that I was going to say "oh, I'll have to die instead", but, you know, I didn't, obviously. But I was ever so glad to go onto human insulin and be able to leave that behind me, because I think it was pork insulin and I wondered so much how they got it, and I still don't know and I'm glad I don't. But I'm on human insulin and have been ever since that time.

Did you notice any difference?

No, I don't think I did. I can't remember what the reasons for putting me on it were, possibly just better control. I mean, the other thing that I have to say is my HbA1cs had been ludicrously good throughout my twenties. I didn't deserve it, because I was not as good as I could have been or should have been, but I think I've only ever had an HbA1c of over eight once, and I know a lot of people work very, very hard and give up a lot of things and don't achieve that. And I

think, you know, I have to appreciate that I have been very lucky, to date. The human insulin didn't really... it was all pretty seamless I think.

(14) How much contact were you having with the medical profession at this time?

I think I was going to Addenbrookes twice a year and having the yearly annual review with all the very detailed checks. But although, strictly speaking, my diabetic medical care had never come from my GP, when I came to Comberton I had a new GP, who understood something that I don't think anyone I'd come across in the medical profession either understood, or certainly didn't feel they had the time or inclination to address, and that was the emotional impact of being diabetic and what it meant to live with it. And he was absolutely wonderful, and has been for all the time I've lived here. He's always understood that and he's been the only person who I think has, so I feel very grateful to him. The hospital were brilliant medically. They did everything they could to help - they were good with advice, with support, in sort of medical terms, but the only person who understood that a diabetic never has the luxury of talking about what it's like to be diabetic was my current GP, and to him I owe an enormous debt of gratitude, I really do.

How did he show this?

He asked me... He was intuitive. He asked me leading questions. His starting point was always "well, life is pretty tough because you're a diabetic and you can't escape that, and it impacts on everything", and constantly telling me not to be hard on myself, and because I was carrying... I did have a burden and that I had to allow myself that, and I wasn't being self indulgent, you know, "just relax, ease up a bit on yourself, you know, you've got to think of something every minute of every day". And I suppose that's the key, that's what I really want to say, that what diabetes means is that. It means never, ever, ever, not for a second, being free of it, and that's what he was talking about and that's what he knew intuitively. When you're diabetic it's like that horrible feeling, everyone must know I'm sure, when you're going to a party when you're sixteen and you haven't done your homework. And you do enjoy the party, you know, it's great, but you know you should be doing your homework. And it's there at the back of your mind, and it's a slight heaviness somewhere. There's something that I can't completely free my mind of, so I can't really enjoy myself one hundred percent, and I'm afraid I think diabetes is like that.

(15) Tell me about the birth of your second child.

Natasha's birth was a very different story. Although I'd had reasonably good control since I came to Comberton - I'd only had one incident once driving a car when I suddenly realised I didn't know where I was. And it turned out I was in my own street, but I didn't know where I was and felt very frightened, very panicked, and came home. And clearly my control wasn't all it might be. And I had various other pressures; I was working as a freelance, I had a little boy at home, a father who came at weekends and was very loving but not desperately

supportive, so there was a lot on my plate, and I think diabetes by then was starting to take very sort of third, fourth. . . You know, in the list of priorities, it was slipping quite dramatically. And when I fell pregnant with Natasha I hadn't been well controlled, and I was anxious about that, and I wasn't sure whether I was going to be able to go through with the pregnancy. I had great fears that I might have damaged her. And decided, obviously, that I would keep her, but I had an enormously difficult pregnancy. I didn't feel like eating any of the things that were good for me; I only wanted sweet sickly things over things that stopped me feeling sick. I got incredibly good care from Addenbrookes. Again, you could not fault the medical professionals - they were brilliant, but unfortunately, in looking after my diabetes, they did miss something pretty significant, and that was that I was fairly dramatically anaemic. And that was actually why I was ill throughout my pregnancy, but we didn't know that until afterwards. So my blood sugars weren't good. I was doing four blood sugars a day - I did stick to what I was supposed to do, I didn't abuse it. I did my very best, but I found it enormously difficult. I slept most afternoons, I never felt well, I felt sick - constantly I felt sick for nine months, and it was a very hard time. And when I gave birth to her, she was a typical diabetic woman's child. She was cherub-like, she was puffed, and that's sad. I don't think I really allowed myself to realise that until a bit later, but when I think of the comparison between Tom, who looked absolutely like a normal little baby, and 'Tash, who was definitely chubby in not such a healthy way, it was sort of more slightly puffiness. And I had a blood transfusion at that time before I was allowed home. And I came home not feeling very well and not feeling very able to cope, and thinking the last thing in the world I needed was diabetes to deal with as well. So, it wasn't a good time. Although, obviously, it was a great joy to have her, I really wasn't very well.

(16) What was it like being mostly a single parent of two children?

It got harder and harder. Of course I'd been totally unrealistic about it. I really do think I was an enormously patient mother for the first few years with Tom, and much less patient with Natasha and both of them as I got older. And I found it much more exhausting, and found trying to fit diabetes in. . . I mean, you know, to be a really good diabetic you need to have a really stress free routine life, and who's got that? You certainly don't have it when you've got two children. So, I didn't miss injections, that was something that happened much more recently, I didn't ever miss injections, but I did feel that support was something I needed and hadn't needed before. And felt that it was a bit hard on Tom, who, by the time 'Tasha came, was four and was being told. . . if you look on his bedstead, my brother's number is engraved on it, because if Mummy wasn't well or if he couldn't wake Mummy in the morning he was to ring Uncle Michael. And he was brilliant actually, he really did take on. You did feel absurd that, you know, you could rely on him, but it didn't feel right that he carried that responsibility. And I guess there I did feel some resentment to the world at large about that.

Were there any times when he had to ring Uncle Michael?

No, he didn't actually. But I remember a very painful day when I hadn't been very well, that's right, I'd been vomiting, and, of course, that's a really joyous experience if you're diabetic - very difficult to control and know what's going to happen next if you're throwing up. And Uncle Michael had said "now you will, you know, keep an eye on Mummy, won't you? You will look after her?", and he said something to the effect of "no, don't want to", or something that showed that too much responsibility was on his shoulders, or at least I felt that... he might have just been saying "no, don't want to" because he would have said that whatever Michael had said, but of course I didn't feel that. I felt he said it because he had too much on his plate.

(17) How did your diabetes progress through the 1990s?

Again, I think I've been very lucky, it hasn't been particularly problematic. And there have been times when I've been very frightened briefly by symptoms that I've connected with - wrongly, as it turns out - with diabetes. One of those was when I got a lot of floaters in front of my eyes and went to the doctor in a panic about it. And he realised why I was in a panic about it - again, of course, didn't need to be told about that - and sent me very quickly to Addenbrook's. And I had the most incredibly thorough tests that went on for hours on my eyes, and, at the end of which, the doctor said something - it's quite interesting, actually, how often people say something in this vein - she said, you know, "you've had diabetes for fifteen years", whatever it was then, "do you realise how lucky you are that you haven't got any complications?". And I wanted to poke her in the eye and say "do you realise how lucky you are you haven't got diabetes?". That's something I've, you know... it's a recurring theme, because a very close friend of mine once said, you know, "do you realise how lucky you are to have had two children without complications, 'cause of your diabetes?". Well, "yes, I do" on one level, but I kept schtum, but I had some fairly rude thoughts about that as well, because I didn't think it was the most sensitive thing that anyone had ever said, because they obviously hadn't thought beyond that into how I might feel. So, I did really very badly want to say "yes, but Ann, you know, I don't feel very lucky having diabetes actually".

And why had you got floaters in your eyes?

Apparently we all have floaters in our eyes and sometimes you get more aware of them. They never go apparently, and I'd swear they had, but I'm told they never go. It's a perfectly normal process of the dreaded ageing. And perhaps I was stressed and more aware of them, and perhaps, you know, this lurking feeling - probably most people have an idea of what their greatest fears about diabetes are, and certainly one of mine is damage to my eyesight. So I only have to have a slightly blurry day or something odd, and I think "oh God, is it an eye haemorrhage, is something going to happen soon, is my luck going to change?" I guess, because I've not got complications. My kidneys are functioning well, I haven't got any neuropathy in my legs, although I've got reason to think that changes are afoot, if you'll pardon the pun, on my left leg there, but that needs looking at some other time.

So no complications?

No complications to date.

(18) Tell me about your daughter being diagnosed with diabetes.

Natasha was diagnosed in June 1999. There wasn't a lot of warning again. It's something I'd always feared, but not as much, perhaps, as people might expect. It wasn't something I was looking out for desperately, although Tom would probably say that I'd attacked him every time he had more than one drink a day. I'm not aware of that, but he has joked that every so often when I say "oh, having another drink?", he'd say "yes Mum, yes it is my second of the day" and "no, I don't think I'm a diabetic" and "yes, I will do a finger prick if you want me to", but I wasn't aware of that. I was never aware of being overly concerned about the possibility of them becoming diabetic. It was a very background issue, but I think it needed to be, because I don't think I could have gone ahead and had children if I thought it was very likely. And my need to have children was desperately strong, so I think ultimately I was pretty selfish and decided to stick that bit of possible knowledge on the shelf. So, when Natasha, who'd been a little bit on the chubby side always, definitely not fat, got a little thinner, I thought how lovely it was, because she was getting her sort of young girl's shape. And then, she often still slept with me, and I noticed her getting up a couple of times to go to the loo at night, and rather than doing a test or taking her to the doctor or a finger prick, I delayed knowledge. I so desperately didn't want it to be true that I actually - it seems absurd now - I actually wrote to her teacher at school and said "has Natasha been asking to go to the toilet more regularly?". And this is totally illogical, because I could have resolved the whole issue in, you know, ten seconds with a blood sugar, but I didn't. I chose... I just couldn't face it, I just so couldn't face it. And I just knew anyway. It's no good people, you know, saying... I did know, I just knew, but I didn't want to. And the teacher wrote back and said "no problems at all", and I thought "yes, it is, though, isn't it? I'm being silly, I'm being neurotic". And then one night she wet the bed, and it was three o'clock in the morning, and I got out of bed and I went downstairs

(19) to my e-mail, and e-mailed... to my computer, sorry, and I e-mailed a friend in Australia, and said "please, please, please be there. My daughter's diabetic - I know she is, I just know she is, she's wet the bed". And I knew I couldn't ring anyone else, but she was going to be there I thought, but she wasn't. And I stayed up all night, and at about half past five in the morning I went round to - guess who - my brother and sobbed all over him, and said, you know, "I know she is". And he, being wonderfully rational and supportive, said "okay, it's blood sugar time. How about I come round tonight and we'll do it together". Because that's the other thing, I just couldn't do it. That's right, Tom had once... there was one occasion when Tom seemed to have something wrong. I think he might have had a bit of a urinary infection, that's right, and I took a sample down to the surgery. I don't think I quite burst into tears when they said there was no

sugar in it, but it was a pretty close run thing. And the doctor had said to me several times “well” - not my doctor - not my doctor who understands, but a different doctor had said “why don’t you just test him regularly?”, and the answer to that is simply “I just can’t”, and I never have, and then he’ll say “I’ll do one” and “should I do one?”. I have never ever tested my son for diabetes, and I’ve got a friend who’s got two children and he’s diabetic, and he checks his children regularly, and I don’t know how he does it, because I’d just shoot myself, I just can’t... that moment when you’re going to know. And it is like that - they will have the high blood sugar; it’s just unbearable. So he came round and we did the blood sugar, and of course it said HI on the machine. And I walked out the house for the next two hours very bravely, and Natasha told her friends who came to the door that Mummy wasn’t very happy and she thought her blood sugar was high. And I went round to the friends, the diabetic, the friends who have got two children whose husband is diabetic, and the mother was great and the father was not so great. He just sort of stonewalled. He just didn’t say anything or do anything or express anything, and it was very strange, and perhaps because he was diabetic himself or perhaps because he’s a man, who knows. He certainly wasn’t very helpful, or maybe it was because I’d mentioned it to him earlier, you know, “do you think there’s any risk of Natasha being diabetic because she seems to be a bit thinner?”, and he completely pooh-poohed it, and said “well, that’s not how diabetes presents itself, you know, she’d be being thirsty”. And, of course, there is some truth in that, but it’s also true that people present very, very differently. Anyway, I rang the

- (20) hospital. I don’t think I rang the hospital, I think someone rang the hospital for me, and - yes they did, the woman did - and said, you know, “we’ve got a newly diagnosed diabetic here”. And they said “come in in the morning”, not get anyone out or do anything at all, which again is interesting because it could have been crucial, I would have thought. But I’m not... my medical knowledge isn’t good enough to really confirm that, but I thought it was a little bit lax. And I took her into the hospital and I begged the nurse to tell me that there was some other reason why she had... that she could have... some other reason there could be that she had sugar in the urine, and she said “well no, not really”. I knew that, of course. But again, I’d been very lucky, because I’d phoned a friend, very close friend, who’d come round and flung her arms round me and said “I’m coming to the hospital with you”, and we’d gone together. And we’d sat in complete horror because, of course, we were surrounded by very sick children; children without any hair, oncology patients, and that was very traumatic. And it was also part of the coping process with Natasha’s diagnosis, because in the way I’d thought “thank goodness, you know, I haven’t got cancer”, here I had a little girl who’s incredibly healthy, and so she’d wet the bed and so she had sugar in her urine, and I knew what they were going to say, and indeed they did. Very shortly afterwards they told



me she was diabetic, and it was very grim. And people were very different in terms of how they talked to me, and I really was very much at sea, apart from the fact it was all dealt with very quickly. They started insulin that day, they were almost going to let her out the same day, but decided it wasn't quite how they'd like it - they'd just keep her in overnight. So they kept us in overnight, and I drove home while Bill held the fort, and sneaked in a bottle of lager to get me through the night, which it did, it helped. And the next morning they showed her - again, I think she was shown on an orange what she was going to have to do. But I walked out with her, and it's a very hard moment when your child says, you know, something to the effect of, you know, "how many of these am I going to have to do?", and you're just stuck thinking, well, you can't think it's for ever, you just can't. At that moment in time you can't think it's for ever, because it would be totally unbearable, so I thought, what you have to think is "well, at the moment it's forever, but maybe it won't be". And we walked,

- (21) walked out, and truly my thought was "thank God it's only diabetes", because I'd seen enough in that time to know I was a very lucky woman and she was a very lucky little girl, so. And we came home, and like people always say children are, she was really, really very good. We got to - I think this was midweek - and we got to the weekend and her best friend Lucy said "oh, can you come round for a sleepover?". And I said "well Natasha, of course you can't, can you? Why can't you?". She said "well, I'm going to do my own injections then", and I said "oh really, you're going to have a practice tonight to see if you can do it then?", and she said "yes, I am". And she wound up the pen, stuck it in her stomach, and said "there, I can go to Lucy's can't I?", and I said "yeah, course you can, off you go, bye!". And she shortly after that started doing her own blood sugars, although pretty reluctantly, and it's a fight day in and day out. She doesn't like doing them. They hurt, she'll only use her thumb, she really, really needs to use her fingers now. She was over injecting on her stomach, until recently when I found the key, and said "oh well, you know, don't we both get sort of a lumpy tummy? You know, what with it being summer and everything 'Tash, and bikinis, don't you think it would just be nice to have a flatter tummy?". And that was it, injections in the bum started immediately. So she's now doing that, which is good, so there's a sort of rotation of injection sites, but not what I'd like and not what any of us would like really, and not enough blood tests and not brilliant control. But incredible support from the hospital, incredible sensitivity. I was told very useful things, really key useful things, and I just go down on my knees and thank some people, different people, who have said different things. The first was a doctor who - I don't think he was the senior doctor - who was standing around the bed, and said to me "of course, in some ways Natasha will be healthier than other children because she'll have a sensible diet". I can't tell you how I've clung on to that. It was the best

thing anyone in the whole world could have said, you know, something positive. And he found it to say, and it carried me, again, it carried me through.

- (22) So your daughter was diagnosed in 1999 and you were diagnosed in 1979. Can you compare and contrast what it was like for the two of you in twenty year gap?

Yes, I think I can. I think it's something I do all the time with Natasha to give her some idea of what the next, well you could say twenty years would bring, but one doesn't say that any more because technical and medical advances are happening much, much faster. So I tell her the stories, and the comparisons are enormous. I mean, I started with the glass syringe, the huge needle, and boiling it in a saucepan, and she's got quite an attractive little pen. I mean, the manufacturers have gone to some effort to produce something that looks fairly cool, and you just wind it up and stick it in. It's got a tiny needle on the top and you don't have to wash it, and you don't have to do anything really. And when I was first diagnosed I had that foul smelling whatever it's called, that sort of surgical spirit stuff, to rub on your skin, which I think they later discovered made the skin hard and therefore wasn't at all useful. And anyway, you don't do yourself any great... you know, there's not enough germs on the skin for subcutaneous injections to be a problem. But she hasn't got to do any of that, no preparation of the skin beforehand. And I could only control my diabetes by how I felt, certainly in the early days, whereas, if she so chooses, which is another matter of course, she can check any minute of the day. If she feels a bit high, a bit thirsty, a bit low, a bit wobbly, she can... and it takes five seconds on her new machine, whereas it took quite a long time, as I remember, with my first huge cumbersome machine, it took a couple of minutes or something. And lots of blood, and that's actually very key as well, because I appreciate this, the fact that you have to draw the tiniest tingiest bit of blood to produce your blood sugar result. And that's very important for kids of course, whereas I used to have to half bleed to death on the stick to get my results. And forever you wouldn't get enough and you'd have to do it again, and there'd be blood everywhere and over the machine, and, or you hadn't got enough and you had to stop it and start again. It was a desperately fiddly, horrible thing. You certainly wouldn't be doing it at work or anywhere in public. It was an ordeal and now it isn't, apart from, of course, psychologically for her. So that's a big difference. And obviously I spent a long time in hospital, which was a pointless exercise, because you don't know how your diabetes is controlled when you're lying in bed. You've got to be doing, running around and jumping and doing everything else, getting over excited, and leading a normal life to know

- (23) how you're going to control it, so her overnight stay was just right, and it meant her control was achieved quite quickly. And her honeymoon lasted about the same time. I think mine might have lasted over two years, but hers, you could see her insulin demands increasing fairly rapidly after the second year. Apart from that, I suppose attitudes, attitudes have changed

in... oh, I don't know if attitudes have changed. I think there's more knowledge about, but having said that I can still be stunned by people's ignorance, and, of course, if you've got a condition and you know a lot about it, which you have to with diabetes, you just forget that people still think "oh, you mustn't have sugar must you?", and that's about it. But 'Tasha's school, who were pretty grim to begin with, got a new Head who got everything sussed and sorted, and got her to give a presentation on it at school. I mean, that was so important, such a brilliant... it was a stroke of genius, it was an absolute stroke of genius. Because she'd... obviously she'd seen me injecting, and she'd seen diabetes could be a way of life, and we don't hide it, and we, you know, sometimes in a restaurant I say "oh, I can't be bothered to go to the loo. Sod it, they don't have to do it, they don't have to look, I'm going to inject anyway". So she'd got the feel that it was nothing to be ashamed of, and for god's sake, you know, children so badly need to feel that it's just a part of life and they don't have to be ashamed of it. But she'd had some very grim experiences at school, being told she couldn't be hypoglycaemic because she hadn't been running around when she was nearly on the floor, being aggressive when she was hypoglycaemic to the Headmistress, and the Headmistress going mad at her, and of course making it a thousand times worse. And she's a timid little thing actually, so why the Headmistress wouldn't think that there wasn't something wrong when this timid child told her where to get off sort of thing; quite ludicrous. So I'd had words with her about that, but it didn't improve. And then we got a new Head, who said... oh, they didn't want to take her on a school trip either, that's right. Her teacher said, you know, he didn't want to be worrying about her at night, sort of basically, and perhaps I'd like to come as well. Well that would have defeated the whole point, and so I stomped into the Headmaster's office and promptly burst into tears, and he said "there, there", and the next thing you knew, 'Tasha was giving a des...dem... to the whole assembly. This little timid little girl was showing them the equipment, how she injected. The whole class was standing up. The headmaster was saying "where's your pancreas everyone? Point to you pancreas!", and the whole of the assembly was pointing - usually in the wrong place, but anyway - to where they thought their pancreas was. And little hands were going up, people wanted to say things, and I suspect they wanted to say "my mum is diabetic" or "my auntie's diabetic" or something. He didn't take questions until the end, but 'Tasha had to ask some questions to see if the kids knew the answers, and they did - they had listened. And it was so, so good for her and increased her confidence in all sorts of ways. And she's got wonderfully supportive friends, who nag her and tell her off and support her and look after her. And that is, I suppose, a long, long way of saying things have changed, because the people around, the kids around and their parents, and their preparedness to invite her round. I mean, all the parents know that she's been in a diabetic coma twice, which is another very dramatic business. They know that's happened and the ambulance

has had to be called, and they still have her round at night. So that's a change in attitude. I mean, obviously I can't say what it would have been like if I'd have been a diabetic child twenty years ago, but certainly it wasn't something people knew very much about or gave you a chance to talk very much about, unless they were quite special, quite different.

(24) Can you tell me about your daughter's diabetic comas?

Yes, they are, well, the two most significant are the most terrifying aspect of her diabetes. I should say that we've learnt a lot about children's diabetes from other children as well. Tom's got a friend whose cousin is diabetic and 'Tasha has met up with her, and they've had a good moan together about blood sugars and about what they don't like doing and what they do like doing. And they send each other letters with needles sticking in their bottoms and "I hate diabetes" and things like that written across them, which, you know, which is great because, you know, why shouldn't they? And they can say that to each other, and they really understand in a way other people can't, so that's really positive. But that particular little girl just falls off the back of chairs and things in comas. She's taken from school by ambulance to hospital on a very regular basis. She's got very brittle control, through no fault of her own, just a metabolic thing. So 'Tasha's got together with her and learnt... we know what can happen there, things can change very dramatically. She made a friend over the internet initially with a little girl called Natasha, and she was absolutely thrilled. Thought it was really spooky because this girl was called Natasha, she had diabetes, she had another brother of the same age, and she'd been diagnosed at the same time; all the sort of marvellous coincidences that kept them friends for weeks. Of course, you might imagine, as children are, she moved on, they both moved on. And since then she's been on a diabetic holiday, which is a great idea, but she was very resistant the first time it was suggested. She said "why would I want to go on a diabetic holiday? Why would I want to be with other diabetics? Why would I want to talk about diabetes? You know, isn't it enough that I have to do as much as I have to do?". And I totally supported that, in my ignorance actually, because I felt like that about support groups. I thought "for god's sake, you know, why would I want to spend any more time thinking about diabetes?", but that was a very unhelpful... My brother has said all along I should join a support group, and I should have done. And I should have been more encouraging, instead of Natasha reinforcing my own views on the 'sod diabetes campaign'; I should have seen the benefits. But she did come round herself the next time. She was saying "well it might... you know, it's doing all this marvellous canoeing and stuff, so, you know, even though it's a diabetes thing, perhaps I might be prepared to go". And she did and had a fantastic time, and made friends with another three or four kids quite closely. And they all have different problems and different things that they love and hate. And they all came to stay here, and it was utterly hysterical if anyone had looked through the window, because come teatime there were five of us shooting up in various parts of our anatomy, surrounded by all the paraphernalia and giggling like mad, and comparing our blood sugars and taunting each other because they

were too high or too low or something. Just generally teasing each other and getting on with it. And that was a good thing, that was great fun, and helped her along the road, I think.

- (25) So then, your daughter had learnt about diabetic comas, but tell me about her diabetic comas.

Yeah, she'd heard about them, because this little girl, as I said, used to fall off the back of chairs and things. But she hadn't had any problem with them, until one night I was woken up at three o'clock, as she was, by then she was in bed with me nearly every night, and she was fitting. And it was absolutely terrifying because I'd never seen a fit, I'd never seen an epileptic fit, and her face was contorted and saliva was running out of her mouth, and she was the colour of... it was just a hideous unbelievable whitey green colour, and she was rigid. No, I didn't know what to do, I really didn't know what to do. I would liked to have imagined I was a sort of coping mother, and maybe if it had been somebody else's child I could have done something more useful, but I totally went to pieces. And if it hadn't been for my son, who's done the journey with 'Tasha, and has even said in the early days "oh, isn't a pity I'm not diabetic too, because then, you know, I'd be really good about it and sensible, and I would teach her and show her, and it would be easier for her". It makes my heart plummet dreadfully when he said things like that, but he's really gone along the whole journey with her, and I just screamed for him. And the first time this happened he was fourteen and a half I suppose, and by the time he came up she was out completely. She'd stopped fitting and she was lifeless, it was just horrible. And I ran down the stairs and rang the ambulance, and he was rubbing Hypostop into the outside of her cheeks; we knew we couldn't put it inside her mouth for fear of choking. And I rang the ambulance because I couldn't be with her, and he could, which is still to me is extraordinary, and it's still true, I'm afraid. So the ambulance came and they stuck the needle in her, I mean had the Glucogen - I had it myself, I could have done it myself if I could have done it, which I couldn't. The needle, it was so huge, and in my mind I'm sure it was even bigger than it actually is, but it's a nasty needle anyway. It's a lot thicker and longer than most of the needles any of us are used to dealing with. And it took her a very long time to come round, and even given that it was night time and everything seems more traumatic and

- (26) longer, then it was a long time. I think they timed forty minutes until she was properly round, which is not good. And they were marvellous, the paramedics, and they said "well, I don't think she needs to come into hospital", which was great, and they said "we'll just sort of check her. What's the name of your dog Natasha?". And Natasha had been trying for ages, she'd been smiling and laughing as she was coming through, but she couldn't say Barney, she couldn't get her mouth - she couldn't get the connection. It's like I couldn't touch the doorknob when I was so badly gone, I couldn't coordinate. She couldn't get her brain and mouth to coordinate, she couldn't say Barney, and of course her animal - she

loves her animals desperately, she really wanted to tell the paramedics about them, and she couldn't. She was smiling and laughing, giggling with them, but she still couldn't speak, and she said "well, we can't go until you speak", and as they started to move out of the door she said "bye-bye" and waved. They said "that's it, we're off. See you Natasha", and went. And then it wasn't very long after that that she had another coma, very much very similar. Again I couldn't cope with... I did try, I did try the injection. I tried because Tom encouraged me, that's what it was. Tom said "I will do the injection, Mum", and I said "I can't possibly let you take that responsibility at fifteen, I've got to do it", and because he was going to do it if I didn't, I sort of tried, but I made a complete cock-up of it. The needle bent in her backside, it bled, it, you know, didn't help. And I ran down and said "it's no good, I'm going to call the ambulance". And the ambulance came and they gave her one, and she came round a lot quicker this time. And on the first occasion, she actually went to school the next day, which seems outrageous, but that was typical of her - kind of "well, that's behind me", not that she knew a lot about it, I suppose, in a sense, but it didn't have any lasting effect. And the second time, she didn't feel terribly well and so she did have a day off school, and I think that's the only time she's had a day off because of her diabetes. And then we all went, well Tom and I went to be taught how to do it and to overcome our fear, well my fear, of sticking the needle in, and making sure that... And they said Tom could do it if I can't do it, and I'm afraid I'm fairly sure I still couldn't do it, but I could let Tom do it. And he's very anxious that I would let him do it, and the medical profession are happy for him to do it because he's been shown, so that's where we stand on that. A couple of other fairly serious hypoglycaemic incidents, one in the morning when she was suddenly crying in the bathroom for no apparent reason, and I realised she was fairly far gone and she couldn't stand. And her friends all came and held her up and we got some glucose in her, and she was okay in the end. But they are very frightening and dangerous, and could be fatal.

- (27) Have you noticed any changes in the way doctors and nurses treat you over the period that you've had diabetes and your daughter's had diabetes?

Well, I haven't had anything grimly insensitive said to me in the last ten years, but in terms of how imaginative they are about giving you the opportunity to talk about what is as important as the medical aspects, and that is the fears you have and what it's like to live with it, no, there's been no improvement on that front. I think my GP's a gem and one on his own.

And how are you feeling now about your daughter's diabetes?

I think we're living it and taking it day by day. And we recognise that, you know, there's plenty more challenges and hurdles to overcome, and she's going to be a teenager and it's going to be more difficult to control. So on that front, I mean, we're just taking it as it comes. The difficult thing, of course, for me to come to terms with is the genetic guilt, because her father had a brother

who was diagnosed at twenty eight with type one diabetes, and I cannot believe that, even twenty years ago, I could have been so ignorant as to not recognise that I was putting pretty heavy odds, or heavier odds, on one of my children being diabetic. So that is a big issue and there's no way out of it. And she did once say, only once she said "it's your fault", but that was one of the most devastating things that's ever been said to me, and I cried so hard she never said it again, bless her, but, and Tom told her off very soundly. But she had made the connection. That's difficult. And the people around me have made me feel differently about diabetes, some of them through being incredibly inspirational. I had a friend who died at the age of eighty, one of the first diagnosed diabetics, first people to go on insulin, and she was diagnosed at eleven, and died of a heart attack, a short five days after her eightieth birthday, in fact. And she's the person, when I have to remember - when I think about what the future holds, most particularly for Natasha, I think of that lady, and how a) she survived to a great age, and b) she lived her life to the full. And I try hard not to remember my other friend, who's thirty five and abused his diabetes appallingly all through his teenage years, and is on a double kidney and pancreas transplant list at the moment, because there are two opposite extremes, and it's really going to be down to her. And that all sounds very negative, and it's very easy to get, when you talk long enough, and you don't get many opportunities to talk about diabetes, but when you start to talk about it, it's very easy to become negative, but there are most definitely lots of positives. I'm grateful, I'm really grateful to have had a chance to realise earlier than most of us must do, unless we are very unfortunate and come across death early in our family or someone close, that I'm not immortal and that time can be short, and you do need to get on and do things while you can do them. And that is such a wonderful thing, and I don't think I've wasted time at all, and I have diabetes to thank for that. And I also feel fairly positive about the future, because I really do believe we've seen enough changes over twenty years to expect that the life of diabetics is going to improve beyond belief, that my daughter's future is much brighter than even mine, and I don't feel despondent about mine.

(28) And would you like to talk too about positive changes?

Yes, I think that there have been a number, but one of the most important is an acceptance by the medical profession now that the patient really does know best. And the idea of an expert patient couldn't be more applicable to a disease than it is to diabetes, and they actually accept that now. And, I mean, we all knew that that was true, even years ago, because when I had Tom, I remember only too clearly wandering around the hospital attached to a drip for days after giving birth. And I knew I didn't need to be, because I had my blood monitoring machine with me, I had food at my bedside, I knew what I was doing, I did not need a drip. Could I persuade anyone to take me off the drip? No, because they hadn't got the diabetic expert there, and everyone was terrified of us. The nurses didn't have the knowledge, and that wouldn't have mattered as long as they didn't mind saying "well, actually we don't have the knowledge". Now they say it. They smile, they're not arrogant, they say "well, you're the diabetic",

and that's how it should be.

Has diabetes prevented you from doing anything that you would have done otherwise?

No, I think I can honestly say that I've lead my life exactly, as far as anyone plans to lead their life, I ever did. In terms of work, I've done exactly what I wanted. I'm a journalist working in the health field and education fields now, and I travel with my job. I've had children and safely. There's really nothing that I can think of that I haven't been able to do. I didn't want to join the army, I didn't want to jump out of a parachute, and I think that's about the only two things that I'd be prevented from doing. I travel around the world on holidays, and with sensible precautions that's no problem whatsoever. Of course, the thing that's most important to me in the world is having children. That's my greatest achievement and my greatest joy, and diabetes hasn't stopped me doing that and enjoying every minute of having children, and it's not going to stop me doing that in the future. I'll have seen them, I'm sure, safely grown up and on their way, and that's really, really all that matters to me.