

78. Greg

(1) Tell me about your background.

Well, I was born in Scotland in 1954. I have one sister - she was born four years after me - and we moved down to England in 1959, when I was five years old. When I was living in Scotland - my children find it very funny about living in a matchbox - but my father was actually an electrician in the steelworks, and we literally did live in a tenement in Glasgow, with outside baths, and my parents have got the photographs to prove this. But he moved down to get a job with Kodak. They did a house swap, and, as luck would have it, in 1959 we moved down to the King's Road in Chelsea, when, of course, the centre of the universe was about to be based on the King's Road. So, it was a pretty fabulous place to grow up, in the sixties. I went to the local primary school, in the shadow of Lots Road Power Station, and there was a wonderful community around there; still lots of bomb sites everywhere - there was a bombed out church just round the corner. And we actually lived in what was called a prefab, which were meant to be there for just a few years after the war, but in fact we lived there right up until 1970. And, in fact, some years back, going to an exhibition at the Imperial War Museum, they had the interior of a prefab, and I amazed my children by telling them exactly what was where around there. They couldn't believe that we lived in such a place. But anyway, yes, so it was a great place to grow up. Passed my Eleven Plus, became head boy of my primary school, went to the grammar school just across the river, and thoroughly enjoyed growing up in Chelsea in the sixties. Went to Camberwell School of Art, shortly after that. Had a great time - art school, glam rock - did my ceramics degree, then went on and did a postgrad in photography. Spent some time photographing punk bands and having a whale of a time in the '77, '78, but I paid for my postgrad myself and had to go back and live at home, which was not much fun. So, I was very desperate for some money, and I'd been doing various odd jobs. My ceramics work was loosely based on East Asian work, so, you know, Japanese and Chinese ceramics, Korean ceramics were very important. I should also say, actually - this is relevant - that growing up in the King's Road, down the World's End, meant that all the South Kensington museums were not that far away, so that was quite a good way to spend a summer, summer holidays. We were all latchkey kids in those days. But 1977, late '77, having finished my postgrad, I saw, by chance - and life is full of chances like that - an ad in the Evening Standard for a job at the British Museum, so I thought I'd apply for it and got the job. And it was there, actually, that I met Harriet, my wife. She was working in the bookshop - my first job was in the bookshop, I moved on to the Oriental Department, as was then - but yeah, we met in the bookshop. We were both living with somebody else, at the time, but it was obviously love at first sight, because within three months, or less, we were actually married. And she told me fairly soon, after we started going out, about her diabetes. Didn't really mean a great deal to me, at that time. My only knowledge of diabetes was my Uncle John, who was still up in Scotland, who I was aware had diabetes, but, as I say, it didn't mean anything to me, apart from these extraordinary looking

huge metal syringes, and a funny chemical smell in his bathroom. But I never saw any effects of it. Mind you, it's hard to tell, sometimes, because he was a sports journalist for a Scottish newspaper, so quite a lot of drinking went on up there! So, yeah, there we go.

(2) What did Harriet tell you about her diabetes?

Well, she told me she'd had it since she was twelve years old, and she was fairly well under control, but, as I say, it didn't really mean that much to me and it was a bit of a learning curve. I was aware that she had to eat at certain intervals, and had to have injections - but sort of interesting watching somebody inject themselves - but we certainly had no adverse experiences that I can think of. Oh, there was one occasion when we went out to the theatre, and it was around Christmas time. We'd all been out doing things and met up there, and she went extremely low in the interval at the theatre, almost collapsed. And I was rushing around trying to fight my way through the crowd at the bar to demand a high sugar Coke for her, because she didn't have anything with her, at that time. But it didn't seem to have that much of an influence on either of our lives, at that time. Things went along pretty well, and absolutely no problems, really.

What involvement did you have with Harriet's diabetes during the first year of your marriage?

There wasn't a huge amount of involvement. I... well, I wasn't totally a control freak, but I tried to make sure that she had glucose tablets with her at all times, especially after the incident at the theatre, and, more importantly, missing the second half - you know, didn't really want to do that again. The only other time that I was sort of very involved was the rather strange incident when she'd been out with her office. She was working for a media company, at that time, so again, a lot of drinking involved. But she'd been out for a meal, and she'd come back home and she really wasn't feeling very well, and she was actually being rather sick, and the sickness went on and on and on. So, we decided - the doctor wasn't very helpful - so we got her off to the hospital. And suddenly alarm bells were ringing absolutely everywhere and discovered that what she had was ketoacidosis. Didn't really know much about it at all, but the doctors tried to explain. I went along with a friend - an old friend of Harriet's who she'd known for years - and the doctors were looking extremely grave, and they said "well, actually, this is touch and go". We thought "my God", you know, "she was just being sick". But it was... she maintains, to this day, that it was food poisoning from some liver that she'd had. But it completely threw her entire system out. But she's always been a bit of a fighter, and, in fact, in almost no time at all, she had recovered, which was great. I went along to see her, and she wasn't in the ward that she was in, she was being rushed off somewhere, and that was sort of panic-making. But she then went back down to intensive care, and... well, actually, we were almost thrown out of intensive care, because she recovered so well that we were causing sort of havoc out there. And there was one scene where - we were both smoking at that time - where we went outside for a cigarette, and she was still on her drip and was accompanied by a nurse.

And this nurse said “well, if any of my colleagues see me now, she wouldn’t believe I’m on intensive care with you two swanning around”. So, that was really, probably, the most extraordinary moment, diabetes-related.

- (3) And then, I suppose, there were sort of minor incidents later on, the sort of mild lows and things, but we were always fully prepared for that. But it wasn’t really until she became pregnant that it had more of an implication on our life. She got pregnant... well, we’d already booked a holiday to go to Greece, and discovered she was pregnant just before we left. So, we were all very excited, and the pregnancy seemed to go well. We were with King’s in London - we were living in Brixton, at that time - and I have to say, the care at King’s was absolutely extraordinary. They were letting her do more or less what she wanted to; they let her go to full term with the pregnancy as well. But there were a few incidents, where there were sort of lows, there were some rushing off to hospital because she was spotting. But it wasn’t really... I wouldn’t say it was terribly diabetes-related; it was more purely to do with the pregnancy itself. But she had very good care at King’s, and we actually had... Dan, our son, was born in ’86 by Caesarean, although it was all planned in, full term, forty weeks. Purely coincidentally, the staff nurse on that night was an old friend of mine, who I don’t think was supposed to be on, but she had arranged to be on. And lo and behold, we had - what was he called? - Dr Kypros Nicolaides, who was apparently one of the best obstetricians - is that the right word? - around at that time. And yeah, I mean, everything went well. I helped out during the... oh, it’s such a shock to the system, no-one ever prepare it for you. They tried to induce her, but it didn’t work, so, in the end, because of Dan’s heart rate fluctuating, it was decided that an emergency Caesarean was called for, and it was something like two o’clock in the morning. I’d been out at the pub with the husband of my friend, the staff nurse. And she insisted that, she said “there’s nothing for you to do around here, go to the pub with Bob”. I thought “oh, all right” - I only had one drink, desperate to get back. And I was sort of helping out, and I was in such a state of shock and amazement, that when I was told to go and weigh the afterbirth, I just sort of casually walked off with this tray with the afterbirth in it, and weighed it and wandered back - they were desperate for me... for something to do. And all went well, and she was... basically, I can’t remember any problems after Dan was born, immediately, with her diabetes.

- (4) And how did Harriet’s second pregnancy go?

The second pregnancy was very, very different from the first pregnancy. The second pregnancy was... well, actually, it was... I suppose you could say it was the third pregnancy, because she’d had a phantom pregnancy in between. We moved to Oxford in 1988, for various family reasons. We’d lived through the Brixton riots, I had a gun pulled on me outside the front door - you know, all the fun things that go on in London - and we decided it was time to move. It

was also the time when the Chancellor was just removing double tax relief, so the housing market was going ballistic, and I have to say, we made an obscene amount of money on a house in London, which then disappeared into this black hole of an unconverted house in Oxford. But we settled in quite well in Oxford, and then, within a couple of years, she was pregnant with Grace. As I say, it was completely and utterly different. Whereas with the first pregnancy, with Dan, everything seemed to be pretty under control - you know, very few lows, certainly nothing to worry about - with the second pregnancy, she was absolutely all over the place. We could be sitting having a normal conversation one minute, and the next minute she was literally sliding off the chair with, you know, severe lows. And I carried on working in London - I was still working at the British Museum, at that point - and I was often getting - days before mobile phones - I was often getting phone calls from neighbours saying "oh, there's nothing to worry about, but we've taken Dan in, and Harriet's been taken off to hospital". "Oh my God!" So, it certainly made me very, very anxious. And although, as I mentioned, I had a reasonable involvement with her diabetes - if only to the extent that, yeah, making sure she had glucose tablets and was eating regularly, and so on, and keeping an eye on things generally - from the second pregnancy onwards, it kind of changed. I felt I had to be that much more responsible - difficult when you're not actually there - but not knowing quite what to do. And so, it was like that throughout the entire pregnancy, actually, that she could slip into lows at a moment's notice, and so, of course, I obviously felt anxious when I wasn't there. We had a good network, Dan was very good and knew what to do, and friends were very good as well. There was also a very different attitude at the JR, where she was being looked after. She was called a... I think Silver Star patient is the term they gave it, at that time. But they were the control freaks, at this time. Absolutely no way was she going to be allowed to go to forty weeks. They knew best. Harriet is quite determined with her diabetes: she maintains - quite rightly, I think - that perhaps diabetics know best about their own individual scenario. But it was very difficult, and so it was quite a fight with the JR. And things didn't go smoothly with the birth - again, it was a scheduled Caesarean. She lost an awful lot of blood, had to have a transfusion, and all the worries about, you know, taking blood, at that time, with HIV AIDS around, and, you know, "are we going to be all right?", and so on. I had far less involvement; I seemed to be kept far more distant. And actually, as it happened, when Grace came out, she was very under size, and we kind of maintain that this was due to not going to full term. And with that wonderful thing hindsight, I wonder whether she had gone to full term, whether Grace, my daughter's diabetes might or might not have developed, because that happened when she was nine years old.

- (5) So, yeah, a whole different scenario here in Oxford. Once Grace was born - and she was in intensive care for a long... well, not for a long time, several weeks - you know, once she was born and back out, then things seemed to stabilise. And again, I don't seem to remember too many diabetic-related problems in the years following Grace's birth.

You mentioned that when Harriet was pregnant for the second time, your son, Dan, knew what to do. What did that involve?

We had told him what to look out for, what signs to look out for. We hadn't actually had a case where we could show him what to do, but we explained that, you know, if Mummy starts behaving oddly - or more oddly than usual! - that he should perhaps help her with having a biscuit or giving her something sweet, or giving her some juice; you know, the kind of juice he would have himself, little cartons. And that if it still carried on that he should call one of the neighbours. And there were always neighbours nearby, because they had... the immediate next door neighbours had a daughter more or less the same age as Dan, so they were always around. And, I mean, fortunately he didn't have to call them I think more than once - I can't remember precisely - although there was one occasion, when they were out together, when Harriet slipped into one of these severe hypos. And that was one of the phone calls: "we don't want to worry you, but..." But yeah, I mean, it was extraordinary that a three year old, or perhaps not... you know, kind of knew what to do, kind of how to look after Mummy. I mean, it's not that difficult, and if it can be related to something that he's aware of, like, you know, "give her one of your juices", I think that's a fairly easy thing for him to do.

- (6) Talk about the years between Grace being born and her diagnosis, when she was nine.

They were pretty straight forward; again, no... Harriet had very, very few diabetes-related incidents. There was one that comes to mind - mobile phones were invented by this point - I was on the bus to London and I got a call from Dan, who had... Harriet had obviously had quite a bad hypo. Her hypos tend to be sort of very early morning or middle of the night, which was very inconvenient. But I got a call around, sort of, 8 o'clock or so. And he'd actually called the ambulance, by that point, because she just wasn't coming out of it at all. We had shown him how to use Glucagon injections - and actually, I'll talk about that and my experience with Glucagon - but he'd been unable to get her round. And she was - I don't know how typical this is with diabetics or not - but sometimes, severe lows, Harriet can become completely incoherent, slightly belligerent and aggressive: "there's absolutely nothing wrong with me, I'm absolutely fine. Go away and leave me alone", while she sort of keels over on the bed and tries to go back to sleep again. So, they thought, quite rightly, that they would call the ambulance. This sticks in Grace's mind. I mean, Grace was being told what to do in emergencies as well, and she was particularly hacked off that day because it was her birthday, so this was "oh, thank you very much for a lovely birthday present, Mum!" But, by the time they'd phoned, the ambulance had come round, they'd given her Glucagon, or whatever, and she was coming round. And I heard this lovely sound of the ambulance drivers singing happy birthday to Grace down the telephone, which was very good! Perhaps what I should say is that I, certainly by this point, was fully trained in the use of Glucagon. The very first time I had to do it, I was stumbling all over the place. I think, actually,

just to sort of hark back, it may have been during the pregnancy with Grace that I first had to administer Glucagon. And if you've ever done it before, you know, you forget, of course, inject the air in first, equalize the pressures and so on, so you're fumbling around thinking "God, how am I going to get this done in time?" and, you know, she's keeling over. And, of course, actually, in the middle of the night, everything seems to sort of take on a completely different timescale, and you think it's forever, and you look at the clock and it's only actually been five minutes. But, you know, in your panic to get things right, it's actually quite difficult. But anyway, I became very good at deploying Glucagon, and we used to joke that I could almost do it in my sleep by, you know, throwing a dart at her, effectively, and hoping it would pump in. We did show both Dan and Grace how to administer Glucagon, but I think, perhaps quite rightly, that they were a little hesitant to do it; you know, it's the idea of sticking a needle into somebody. Certainly the first time I did it, I was extremely cautious, and, you know, I made sure I didn't hit a vein, and it was always into the thigh or the bottom. But, I won't say I became blasé by the end of it, but, you know, I thought "well, she's unconscious, she's not going to feel anything. As long as it goes in, it doesn't really matter. Get it over and done with quickly". Yes, actually, it may have been during the pregnancy that I had to give quite a few, but there certainly were more in later years as well. But, apart from that, and apart from the occasional lows, there wasn't really much of any great concern, I don't think, until Grace became diagnosed with diabetes, and then a whole different chapter begins.

(7) Tell me about Grace's diagnosis.

Well, we were on holiday in the summer in Brittany, in northern France, where we used to go to quite regularly. Grace always had, and still has, a sweet tooth, and we were suddenly aware that she wasn't drinking her usual industrial quantities of Orangina, and was just asking for water instead. And this didn't ring any bells with me, particularly, but it did with Harriet, because, of course, this was exactly what had happened to her when she was diagnosed, as a twelve year old. So, Grace was nine, at that point.

What year?

That would have been 1999. She's always been a skinny little thing, and, you know, we hadn't actually noticed... although, looking back on photographs of that period now, she was, of course, much thinner at that time. So, as I say, Harriet was concerned. We were on holiday. We weren't going to break the holiday - there was nothing particularly untoward with her, except that she was going to the loo a lot. I think she may have had a slight infection as well. But almost as soon as we got back, Harriet made an appointment with the doctor, took her round. Do you know, I can't remember whether we checked her blood, at that point, or not. And Harriet always carried her blood-checking kit with her, but I can't remember whether we checked Grace's blood, at that point. But anyway, when we got back, Harriet rushed her round to the doctor's, and she was in hospital that night, and, you know, it seemed fairly sure that it

was diabetes. I was in complete denial; I refused to believe it was. I suppose, having that extra responsibility of looking after one diabetic, and two children... but then looking after two children, one of whom was diabetic, and, you know, an adult diabetic, was perhaps something I just didn't want... didn't think I particularly wanted to come to terms with. But Grace was in, and, you know, she'd had, for better or worse, she'd had experience of her mother's diabetes. But she'd coped with it. I mean, the incident on the bus, when I was called on the bus, and she and Dan had called the ambulance happened when she was... it was on her seventh birthday, and Dan was ten, coming on eleven. So, I think that was the most severe one that she'd dealt with. And she'd seen me, I think, dealing with Harriet's lows very early in the morning, you know, either with juices or with Glucagon, and sort of hearing the noise, coming in and saying "can I help?" And, you know, she was fine. So, she was aware of what there was, but she wasn't fully aware of the full implications regarding herself, and the fact that that was it, she's stuck with it now; you know, it's not something that she will get over. And she was very, very good about it.

- (8) It perhaps helped, in a perverse way, that her best friend has got cystic fibrosis. And they used to play off who was worse than the other. You know, "oh, well, I've got a drip in", "oh, well I've got two drips in", and "I've been in for four days", and, you know, so... They would come along and try to outdo each other, in hospital. And her best friend was often in the JR, at that point, as well. And she got very good help, to start with, at the JR. I'll come back to some of the less good aspects. But she got very good help from everybody there, at that time. Again, very, very different from Harriet's experience, where, as a twelve year old, she was kept in for three weeks, forced into hypos so she could know what to do with it. And I think Grace was out... she was certainly out well within a week, she may have only been in about three or four days. And, in some ways, I think we were sort of left to deal with it ourselves, which, you know, is fine and good. And it helped that we had a family history with diabetes, so we did know what to do with it, but we did wonder what would happen to other people who were completely new to this, and had no idea. And there was a young lad in, around that time: skeletal, I couldn't believe that he'd got to that state. His parents just didn't know what to do at all. I just hope they got better support than we did. But, I mean, that's not to say that we had bad support. So, we had all this discussion about what she could eat and what she couldn't eat. It kind of knocked her sweet tooth a bit on the head, although, you know, she still has a propensity for sweet things. And we were giving the injections; Harriet was doing it mostly, but I was doing it as well. But it was all this strict "right, you're going to eat this, going to eat that. What are you going to do? What exercise are you doing?" and so on. And there were some fights, there were certainly some fights, and, you know, "I don't want to do this," and "you've got to do this". And, you know, "no, you're not going to give me that injection", and so on. And so, it actually came to one point, we said "well, we'll just

leave it there. You know what to do". And that was it, she did her own injections, and, you know, it's been like that ever since. She's been pretty much in control of her own diabetes. It's changed over the years, but we'll talk about that in a minute. But yeah, she's been very much in control of her own diabetes. But I have to confess that it really has changed all of our lives, having two diabetics in the household, and changed again, drastically, when Grace was diagnosed with epilepsy as well.

Before we get on to the epilepsy, you said that you were in denial about Grace having diabetes. How did you feel when you could no longer deny it?

It was actually quite a shock; it really was. You know, I mean, having been married to Harriet for so long, and having got used to her diabetes, I suppose I was, in some way, fairly complacent about it. But when you've got a child who has it, you know, there are far greater responsibilities there, and, you know, you just don't want it to be there; you really don't want it to be there. I knew that it was going to have a lot of implications for her, and dealing with that, I think, was just something I wasn't happy to face. I mean, we did - of course we faced it, but, you know, I don't think there's anything wrong with saying "I don't want this to be, I don't want this to happen", you know. And I fought it for a long, long time. I mean, in the face of all the evidence, it was fairly obvious it was diabetes. But, you know, "well, it could be something else; you know, it could be running a fever; you know, she has highs and lows; you know, check my blood to see what that is in comparison". You know, I mean, I suppose you do anything to avoid your own child having some long-term condition. I don't want to call it an illness, it's not an illness; you know, it's perfectly liveable with - at least, Grace is finding it perfectly liveable with. I know some people have the most awful problems with it. But, you know, we've lived with it through Harriet, I've lived with it through my Uncle, indirectly, and, you know, we've lived through it with Grace as well, and just take it as it comes.

(9) And then you said Grace developed epilepsy. Tell me about that.

Yeah, well, that was another "this isn't going to happen, isn't going to be". And, actually, I think to this day, we're still not convinced; I think the jury is very much still out on this one. But she was about ten years old, so around 1990. I was away on one of my foreign trips - yeah, actually, sorry, not 1990, that's when she was born. It was about 2000, spring term - and I was either out of the country, or I was on my way to work, I can't remember exactly. But I had a call to say that she'd collapsed at breakfast. And Dan helped out on that occasion there. And she very quickly came round, and I thought "oh, well, she's had a hypo"; you know, she'd had a couple of mild ones up until then, so... Perhaps I actually ought to talk a little bit more leading up to that point, as well. Sort of following on from the 'in denial', and having got over the denial part, I suddenly learned to sleep on an absolute knife-edge, and I'm not sure that I've actually got over that one yet. I now sleep very lightly. You listen for every sound that's happening in the night, and you get very accustomed to the sound of somebody having a hypo. Although, disturbingly, where we live



now, in spring and summer-time now, it's hard to differentiate between a hypo and the damn pigeons that roost on the roof, because the noise that comes out is not dissimilar. And I've threatened Grace with making a recording to play back to her, so that she knows what the two sounds sound like. But, anyway, there was this collapse in the morning. And, you know, if you have a bad hypo, you'll collapse, but it was sort of more than that; it was slightly odd. So, it was discussed at clinic, and the suggestion of epilepsy came up. And she had all the brain scans, ECG, you know, she had absolutely everything going, and she was absolutely clear. And I suppose our big... - and she was put on Tegretol, as a drug for the treatment of epilepsy, but she was put on a very mild dose - but our great argument has been, the whole time, both with the diabetic clinic and with the epilepsy clinic, is "you tell me the difference between a severe hypo, and an epileptic fit". And they can't, they absolutely can't. They can say that she has a propensity to epilepsy, which might be brought about by low blood sugar. And, of course, in typical hospital way was "oh, well, why don't you check her blood sugar while she's fitting". Yeah, right. You know, I mean, she was ten years old, and she's seventeen years old now. You try holding down a child of that, and say "I'll just check your blood, dear", while they're fitting, or having a very, very low hypo. As I say, the jury, I think, is very much out on it.

- (10) At her last clinic, with the... Well, we finally persuaded - this is a very interesting one - we finally persuaded the clinics to recognise the fact that Grace was a person, she was not a) an epileptic and b) a diabetic; she was one person. And yet, the two clinics were treating her separately, independently. So, we finally managed to persuade them to hold a joint session together, which they said "oh, what do you want that for?" Both Harriet and I were saying "well, to talk about her condition", because we were having this argument with the epilepsy clinic about is it epilepsy, is it a severe hypo, and ditto with the diabetic clinic. So, they got together, and we talked about all sorts of things. And it was quite interesting to hear both the consultants say to each other, at various times, "oh, I didn't know that". The result of this is that... I mean, Grace's medication for her epilepsy has fluctuated up and down. At the time of the clinic, the medication that she was on was below the working efficiency. She has subsequently reduced it even further, with still no adverse effects. I mean, I suppose what we're trying to say is "why is she taking this medication?" which obviously has health implications. The first - was it the consultant or was it the doctor? - was the most insensitive person. "Oh, and, of course, if you take this drug, you'll get very hairy". Great, that is really good. You say that to a young girl - I almost thumped him. I mean, it is completely and utterly insensitive, and she's been very sensitive about that ever since. But she's managing both very well, now. We did have a lot of night-time hypos, which had to be dealt with. We dealt with them - and this was in the early days, around the time that she was diagnosed with epilepsy - so again, we got very handy with the Glucagon. But, as she said "Glucagon makes me feel absolute crap, so if you can avoid giving

it. . .” But actually trying to get anything else down someone in the middle of the night, three o’clock in the morning, as it usually is, as I say, it is extremely difficult. And we did check her blood sugars, we did manage to check her blood sugars sometimes, and they were always very, very low. So, you know, you tell me: is that an epileptic fit, or is it just a severe hypo? And yet, curiously - I don’t know how many diabetics are like this - you know, Grace can walk around, as she was last night, with her blood around two, slightly incoherent - we thought she’d been out drinking - and, you know, she was absolutely fine. And yet, other times, it’s four and she’s absolutely all over the place. So, it’s quite tricky. But, she’s a seventeen year old girl now. She goes out. We’ve talked to her about the risks that she takes. Well, she’s had two severe hypos, one quite recently, after she’d been out clubbing. The other one was in France, but I’ll come back to that.

(11) Tell me about these two severe hypos.

Well, the one after she’d been out clubbing happened the night after she’d been out clubbing, but, you know, she’d been out till something like four in the morning with her boyfriend. Alcohol was involved - she certainly shuns drugs, we are aware of that - but, in a way, it wasn’t unexpected. She’d been out, she’d been exerting herself, she perhaps hadn’t been eating properly, she had been drinking, so not unexpected. And again, as far as we can tell, it was a severe hypo, but, you know, the epilepsy clinic might say “oh, well, it’s epilepsy”, but, you know, she’s not susceptible to the lights. The other one was when we all went on holiday to France. She went and stayed with relatives, Harriet and I went off on holiday without children - first one for more than twenty years, well, almost twenty years. And Grace was staying with French relatives - we have got a few French relatives in France - and it was the time of. . . was it the World Cup? Yes, when France lost. And again - no, sorry, it wasn’t the time that France. . . that was another incident. It was a wedding that she’d gone to - and again, you know, she’d been dancing till all hours, she had been drinking, she hadn’t been eating properly. And we were in Paris, she was in Normandy, and we got a call to say that she’d had this hypo or attack, or whatever, in fact had had it twice, and they’d tried to bring her round. The irony is that she was surrounded by French doctors, who didn’t seem to know quite what to do with it, probably because they were immensely hung over as well. But her cousin and cousin’s partner are both doctors, and perhaps should have been a little better prepared for dealing with something like that, so we certainly did rub that in. But yeah, she was fine. We asked if we should go and collect her, and she said “no, she’s recovered”. Just slightly worrying that it was sort of one attack after another, and really quite rapidly, so we were concerned about that. There was another incident with the World Cup, but that was a minor hypo, again in France, so we’re sort of slightly concerned about her going to France to rather large festive occasions!

(12) And how has she been when she’s been at school?

Well, it was actually very interesting that actually she was diagnosed with diabetes within the first week or so of starting her new school, Greycotes. She's then moved on to Oxford High. The school have been... had been - she's moved on now to Cherwell, for the sixth form - but the school had been really quite good about the whole thing. They have very good pastoral care there. Understandably, they were concerned, I mean, certainly in the early days when she was getting used to it and getting stabilised. But we had emergency kits left all over the place - little boxes, you know, with juices and so on - the teachers were aware of what could happen, what the symptoms were, the diabetic nurse came in and talked to both schools. But to be perfectly honest, the schools didn't have a great experience of dealing with diabetics. I think there was one other, at one point, in the junior school, and maybe two others in the senior school. But there were certain prejudices about what she could and what she couldn't do. You know, she's a fairly active girl - mostly, when she's not blobbing watching television - but, you know, she can swing from being very active to being extremely inactive, but why not? But there were a couple of incidents on school trips where she'd gone low, and had to be dealt with, and that kind of clouded the school's perception. I can't remember whether once they actually said "it's probably not a good idea that you don't come on this", but the implication was certainly there. It was also interesting, actually, that she also went on one of the children's diabetic camps, and had a severe hypo there as well, so that gave them something to do! But yes, there was this perception that, you know, she couldn't do these things because she was diabetic, and it wasn't because she was diabetic, it was just that they couldn't... they didn't know how to cope with it, didn't want to cope with it. They went on a trip to the Cheddar Gorge caves, and she wasn't allowed to go down into the caves with her. I mean, I took her back, and we had great fun slithering around in all the mud, and so on. You wouldn't get Harriet inside there if her life depended on it! But, you know, that was exactly the thing that Grace liked to do. And I've got some photographs, which we'll show you, of her abseiling and rock climbing, and so on, and that's exactly the kind of thing that she liked to do; perhaps less so now she's seventeen, but she's still reasonably keen on it. But yeah, her school years were generally pretty good, generally very few problems. You know, as I say, the pastoral care was pretty good, perhaps a little over-protective at times, you know, while she was at school. And then there were these incidents of, you know, the school trips - well, can she or can she - and I think, you know, that was something we weren't terribly happy about; neither was Grace.

(13) Can you talk about how Grace has coped with her own diabetes, over the years?

Well, from the beginning, once that she started doing her own injections, she's pretty much been in control of her own diabetes, but with a lot of input from us. And it's very difficult to know how much to back off, and how much to let her just go with it. And I still think... I think, even now - you know, she's seventeen and a half years old now - she still comes to us and says "what's for dinner?" - good - and we tell her what's for dinner, but then she'll often say "well, how

much of a jab shall I do?" "Well, that's down to you. You're in control of your own diabetes, you don't need us to tell you what to do"; you know, that's the way we've always run with it. So, there is that still there, there's the letting go. There's the letting go on both sides: you know, the letting go control of our side, and the taking more control on her side, and, you know, she's getting there. And I think it's possibly, you know, just this sort of parental worry that... we look at all the eventualities, and, you know, she's a teenager, and teenagers have their minds on different things. So, we do say, you know, "if you're going out, try to make sure you eat before". Yes, she doesn't drink a lot, you know, she enjoys a beer or two, but, you know, we pointed out to her actually that beer has actually got quite a high carbohydrate value. You know, if you're going to drink a couple of pints, a couple of pints have other effects as well, so... There's still a lot of things that she doesn't know about, she's still learning. I mean, we're all... of course, we're all still learning. But, for the most part, she tries to keep control of her diabetes. But it does lead to sort of storms and tempers, sometimes. You know, "I know what I'm doing, you don't know what I'm doing", and harks back, very much, to how Harriet felt about her own diabetes. You know, Harriet maintains that diabetics are the best people to know about their own diabetes, which is absolutely right. Grace is getting there, hasn't quite got there yet, but, you know, she's working on it. And there are obvious concerns, as well. You know, she's going to be finishing school this year, going off on a gap year, all the risks that happen with a gap year. So, I think we just want to be sure that she's absolutely stable, absolutely comfortable, and doesn't have to ask those kind of questions, once she goes off by herself into the big wide world. I mean, Dan's in his final year at Uni now. You know, he went off, and it was bad enough seeing him off, actually, you know, leaving the nest, because he had no medical conditions. But, you know, with Grace going off, I think we want to be absolutely sure that she's absolutely fine. I think she feels fine within herself, but maybe she's still questioning, as well. But there is the - you know, from us as well - you know, just back off, leave her to it. And yet it is very, very difficult, because there are those great, great concerns. Yes, it's a tricky thing; I don't know how you ever get over that one.

(14) And can you reflect on Harriet's diabetes, over the years, since the children were born?

Well, since all the dramas and crises of the pregnancy with Grace, Harriet has been pretty stable, I think, for the most part. I mean, I can't actually remember the last time that I actually had to deal with a severe hypo. Yeah, there've been lows - there are lows in all relationships! - but, you know, a diabetic low. I do keep an eye on things, I do still sleep on a knife's edge - you know, night-time noises are a complete nuisance: "is that a hypo, is it just someone coming in, is it a pigeon?" But Harriet, for the most part, as I say, she maintains the diabetic is the best person to analyse and say how their diabetes is being managed. Of course, she goes to clinic the whole time, and there are, you know, there are concerns about blood pressure, and, I mean, everything that goes with diabetes, and taking care of the feet, and taking care of the eyes. She was the first to

admit that her teeth were in an awful state, but I'm sure that can't be blamed on diabetes. But there are all those medical conditions. And I'm always saying to both Harriet and Grace, you know, "have you still got your glucose tablets with you?" "Why has the bottle of Lucozade run out in your room, just in case?" "Are there enough juices in the house?" and so on. So, the sort of general, you know, just sort of keeping an eye on them, which was not something I imagined I'd be doing in my life. There are other things as well. I mean, we went down to the West Country recently, Harriet and I. Grace went off with friends, staying in Lyme Regis, and we went off staying about ten, fifteen miles away, just in Devon. And, of course, there were concerns that Grace would be all right, and, of course, she was perfectly all right, as all right you can be in a holiday house full of seven or eight girls. Goodness, I don't think town knew what had hit it! But, you know, we were away, but Harriet and I were off and, you know, we were having a lovely time, and we were doing the walking of the south west coastal paths. Actually, there were some... they weren't lows, but she was finding that actually, having gone from a... I can say a relatively sedentary life - you know, she cycles, she walks, she tries to keep as active as possible, but it was a very different type of activity when you're out walking all day - and there were a few instances there when she just said "yeah, I feel really odd". And the bloods were up and down all over... the blood sugar levels were up and down all over the place. And you kind of think, you know, we have this great wish to go on lots of walking holidays, and I can see that the diabetes is going to interfere with that. You know, there are lots of things that we enjoy doing together, lots of things we enjoy doing separately. You know, I'm quite keen... I have a very different approach to how I'd like to go out walking. You know, Harriet likes to stop every hundred yards and admire the view. I want to go for it, see the horizon and reach the horizon. Of course, you never reach the horizon, you just go and on and on. But obviously, her diabetes is having... will have some impact on how we do that. I mean, other than that, looking at those kinds of things that we might be doing together, I don't think the diabetes has made too much of an impact, and she keeps herself reasonably healthy, is aware of all the risks involved. Grace, I hope, is also being fully aware of all the risks that are involved as well, but, you know, teenagers' minds are elsewhere. It's always there, it's always going to be in the background, it's always going to have to be considered, and it's something we're going to have to live with. I mean, we'll go off and do our walk. I don't think... we had this great wish... well, actually, Grace and I had this great wish to do the entire Santiago de Compostela walk, over about three months. I think Grace wanted the slap up meal at the end of it, you get if you get all the stamps in your pilgrim's pass, but that's something you might have to work towards very, very slowly. But, you know, we're looking at it. But I'm... I suppose, to be perfectly frank, you might think, well, actually, it's holding me back, because I would love to just go off and do it. But, you know, there are other commitments everywhere, you know, in our lives, so we can't all do what we want to do, so that's tough; you live with it, go and do the best we can.

(15) And can you talk about how your son has coped?

Well, Dan is three and a half, almost four years older than Grace. And certainly from the earliest times, as I mentioned earlier, you know, he's helped with Harriet when there have been problems. He certainly helped Harriet with Grace when there have been problems, as well. You know, there were the incidents... Yeah, I work in London, so I leave early in the morning, come back late at night - well, not late at night, seven thirty, eight, something like that - so mornings can often be the difficult time. I also go away on business quite often as well, overseas, so I can be away a lot. And actually, Dan has been great, you know, he's helped a lot. And when there have been problems with Grace, Harriet - who's quite small - has had physical problems dealing with Grace, so Dan has been great on that. I mean, he's not a strapping twenty one year old, but he's all right. He's a wiry twenty one year old, and, you know, he's been able to help with those hypos that Grace has had. You know, if nothing else, just providing moral support, if not the physical support, because, as Harriet has said many times, you know, "I'm just not strong enough to deal with Grace when she's in these states". And, you know, fortunately there haven't been too many of them, of late. But yes, simply getting her into the recovery position, let alone checking her blood, and trying to get glucose tablets, or whatever, down her. Yeah, Dan has been great with that. He doesn't talk about it very much, you know. He's aware that it's there the whole time. You know, he's been at Uni for almost three years now, and so hasn't been at home a great amount, but, you know, he's aware that at meal-times there's always this, you know, "what are we having? What are we going to eat?" blah, blah, blah, and so on. He's sort of there, quietly in the background, and always seems to know what to do, you know. I mean, he's been told what to do, but instinctively, he knows when he's needed. Despite the fact that he's - he was a late teen, I mean, he's now a twenty one year old - and it would take an atomic bomb to rouse him, you know, actually, when called, he will come running up the stairs to help. But, as I say - touch wood - you know, there haven't been too many of those recently. But yeah, he's been great, though. We were also part of a family programme - I can't remember the name of it, now - where we were all checked, parents and grand... It was looking through the generations to see who had the propensity. And I think Dan was secretly, or quietly extremely pleased to know that there were very, very little chance of him having diabetes, at any point. I'm not quite sure how he would have coped with that. I'm not quite sure how we would have coped with that, either. But I think he was very relieved to hear that. But no, he's been a great help, certainly.

(16) And would you like to reflect on the role of medical staff in both Harriet's and Grace's diabetes?

Yes, I mean, the... I think I mentioned already the concerns with the clinics, about her not... about Grace being treated as two separate people, with the diabetes and the epilepsy. But, yes, for the most part, the people in the clinics have been extremely helpful, the dietitians, and so on. And certainly, over the

years, we've built up a quite good rapport with those that are still there. I mean, the difficulty always lies when you build up a rapport with somebody, and then they move on. There was an extremely good consultant at the - not to say the consultant there now is not good - but extremely good consultant, some years back, who then moved on to do research elsewhere. And he seemed to really understand, you know, what a child was feeling, and how he should react to a child. I should mention the diabetic nurses have been extremely good. Grace has always built up a very good rapport with them. I can't remember precisely how many we've had so far - two at least, possibly three - during her time there. And they're very good; you know, they text each other, they phone each other. Generally speaking, responses are good. There have been some times where, you know, we've left messages, and there's been no response for days and days and days. You know, you can understand that they're busy, but when you've been asked to contact them, and then you contact them, and then they don't get back to you, that's a little bit concerning. But no, generally, for the most part, Grace, certainly, has had really good support from the diabetic nurses, especially, but also from the other people in the clinic. I'm less aware of how Harriet has dealt with her clinics, but all I can say is "God help them", because she's a very determined woman! And, as I say, you know, she says that - quite rightly, I think - that she knows pretty much best about her conditions. But obviously, you know, she listens to them. She's changed her regime, now and then, different types of insulin, and so on. But, yeah, a very determined lady, so, you know, if they ask the wrong questions, they will be told in no uncertain terms. We had one incident with Grace at the clinic, actually. It was when we'd set up the first of these joint appointments, and, in fact, neither consultant turned up, although the diabetic nurse was there, being very diplomatic - a great girl - but also fielding this poor, defenceless young consultant, who was along trying to fill in for both of them. So, yeah, all credit to the diabetic nurse, at that point, for sheer diplomacy in dealing with what was... well, we were absolutely furious. One of the consultants said that they weren't aware the appointment had been made - we had a letter. The other one said... I can't remember what the excuse was, but it was just very, very unacceptable. So, they were very, very apologetic the next time, and have been sweetness and light ever since.