

(1) Tell me about your background.

Well, I was born in Broxbourne, in Hertfordshire, in 1964. I've got two brothers and two sisters. My parents were both teachers. And then we moved quite swiftly, when I was two, to Crawley, which was then a new town. Quite a nice place to grow up - big, massive council developments, basically - and they had an actual house set aside for them, because they were teachers, which is pretty much unheard of nowadays, I would say. So, we moved there, and that's where I grew up. I grew up there - I left home at eighteen to go to university, so my whole life was there - so it was a nice place to be; we were near the countryside.

What sort of schooling did you have?

My schooling: it was your local state schools, really. Went to the local infants, went to the local juniors, and then on to a pretty big school - Ifield School - for my secondary education, which had been a grammar school when my brother started, and by the time it got to me, it was a pretty grim place! It's educational in its own way. I mean, I enjoyed school. I mostly enjoyed my sport; that's what I really liked, sport and history, that's sort of pretty much what I enjoyed. But we all went to the local schools, until my parents had had enough, I think, of Ifield School, and moved us all across to another school across town.

A private school?

No, it was still a state one; it was Hazelwick School. And really, the reason we went there - my brother had gone, by then, my eldest brother Tom - my sister Jane was into music - she's a cellist now - and they did A Level music, whereas they didn't do A Level music, so everybody else got taken over to the other school, so... I mean, they would always... they didn't have any money, so they wouldn't have sent us to private education anyway, but they wouldn't ethically, I suppose. Their morals weren't that they would send us to those sort of schools, I suppose. So, yeah, sort of left wing upbringing, I suppose, liberal. Not religious, although they both met through the Catholic Church, hence five of us!

And did you know anything about diabetes before your older brother was diagnosed with it?

No, nothing at all. Ah, well, I had an uncle - not related - who had it, but it wasn't in our consciousness, and I don't think my parents really thought about it at all, because they didn't recognise it when it came along.

Tell me about your brother's diagnosis.

As far as I can remember, I think it was... took some time to come to my parents' sort of understanding. My brother just got very, very thin. And I do remember him being thin, but didn't matter to me; don't care. He was an older brother, teenager; he wasn't particularly communicative - he was a, you know, a proper monosyllabic teenage boy. So, he got very, very thin, and so they took him to the doctor. The doctor recognised what it was, and he was pretty ill by the time he got into hospital, and so he went to the local Crawley hospital,

which is now shut. And for me, from my point of view, I think I kind of lost track there. I think he had a few weeks in hospital, where they kind of trained him up. I don't think they do that now - I'm guessing that's not a great thing to do, to keep them sort of institutionalised while they teach them to use the equipment - but it was what he had to do, I suppose, or that's how they felt they had to deal with it. So, yeah, I remember my Mum telling me at the school gates, and I think she was pretty terrorised, probably, even then. I do think she looked completely... yeah, overwhelmed, I think, by it, so I didn't really understand what she was saying. I wonder how I explained it now, to myself, but I think, at the time, I didn't really... I knew it was very bad, and that was it. And then we went to see Tom, and he seemed quite well, in hospital. And, you know, I've been thinking back, and you get images in your head, and I just associate certain images. So, the orange that we talked about earlier, that he's been practising on an orange, which meant nothing to me, and I actually probably think it probably meant nothing to Tom, because it's nothing like injecting yourself, injecting an orange, in any way.

(2) What are your memories of what the hospital was like?

Well, I hated hospitals, actually. It was funny, I had a mini-phobia, so I wasn't a grand fan of it. And there was... I don't think he was in a special unit, I think he was on a ward with just other folk. That's what I remember. It wasn't... it's funny, I don't think he was having a bad time, I didn't think that it was a sad moment, when I went to see him. So, the memories of hospital were just visiting Tom and getting bored; that's how it was for me.

So, he came out of hospital in 1973, when he was thirteen and you were eight. What are your memories after that?

Okay. When he came home, I think there was a period when it was all about that. So, I remember sitting... examples like sitting at the table, and if we were going to have some chips - he had a book that he brought home with me, which showed him what he could eat, and the amount of which... Which, at one point, I remember my parents must have had some sort of sense of "let's not just take everything as read", 'cause it worked out that he could have two and a half chips, or something. Which, you know, that's not how you balance your life, is it? So, I think that they were aware that, although the book was used - it was definitely used, and out and about - but I think, slowly, as Tom started to live with his illness, he worked out for himself that this... But the scales were out. I remember scales being out, and things measured, you know, and that was only when Mum made a cake, previously, so... And there was a preciousness about it. They didn't try and make him precious, but he was the oldest boy in the family - I'm sure that had something to do with it - they didn't have a clue. My Mum, I'm sure - I mean, I talked to her about it today - she feels guilty, so you're trying to make up, I think, you're trying to make them all well again. But, of course, you never can. And there was lots of paraphernalia, which was fascinating to me. I mean, my brother was into making his own films, and editing his own stuff anyway, so I think, in a way, Tom... He had this box,

I remember, a Tupperware box with white spirit in it, and a syringe that, now I look back, looked about a foot long, but it was probably shorter than that. But it was metal and glass, and, you know, it was in that box, and you didn't go near it. And it smelled, and I think his insulin was in the fridge, in its special place. So, things had changed, there was definitely a change, and I think that it was a big learning curve for my parents and Tom. And I think that we kind of just... like I say, those visual things and those smells, maybe I could smell the... I keep calling it white spirit... yeah? Those are the things that I remember about Tom coming home; it's a visual thing. And, probably, my parents didn't tell me enough. You never really do tell kids enough, 'cause you're probably either too busy dealing with it, or you don't think they need that information. But more information would have been great, because I didn't really know what was going on with my brother.

(3) Why did your mother feel guilty?

Well, having spoken to her subsequently, I think that a) she didn't notice it straight away - and when we look back at pictures of Tom, he was stick thin, but, you know - and b) because I think she thought, somehow, she must be to blame; these things can't just crop up. And diabetes is one of those things that you can't explain. It's not like having a car crash and losing a leg, and there's an explanation there, or, I don't know, having asthma, and knowing what you're allergic to; you just get it. Although, there's lots of discussion about how you get it. And I think, then, that she's a mother, and that's what you do. You start to look for someone to blame, and you end up blaming yourself, so I think she felt guilty. And I think that probably found its way through to Tom. I think he kind of... he probably used that, over time. He wasn't a horrible person, but I think he got special treatment, probably, at times. And there's funny things that you don't explain to the kids. How can you explain the ins and outs of how diabetes works? You say "he cannot have sugar, he cannot have sugar", and then he gets the cream bun, you know. As a younger sister, you think "hang on a minute..." And there's not really an explanation that's going to work, it's just how it is, and that's it, so... If I'm looking back and being a nine year old, those are the things I noticed, you know. You'd got to be careful... there was an element of being careful around Tom, and we probably didn't need to be, but we were. So, he could be angry, I remember that - he was allowed to be angry, and there was a reason for him to be angry. So, when you talk about... when you said to me "when he came back, what was it like?", the things that I'm now remembering are actually feelings, rather than practicalities, I think. And that's, probably, when Tom came back, that's what happened.

(4) How do you feel that diabetes affected your brother?

I think, you know, I've used the word angry before, and I think there was an element of that - I think he was angry. I think he was a teenager, so it's hard to pull apart the things. I know there's a couple of things, as he grew up and went to University, so if I can talk about that, and imagine that he felt like that... He was an artist, so he did fine art. And eyes and diabetes - you know, your

eyesight and diabetes are very closely linked - so he had, you know, I think, from the age of about sixteen, he was worried about that, and quite down and quite frightened. And angry, which is a word that keeps coming back. I mean, he's never thwacked anyone, as far as I know, but that is something I associate with him. So, I think the fact that he wanted to paint and be a painter, and his eyes would let him down one day, probably had a significant part to play in the way he thought about it. And I know that when he was at university, he did freak out. I think he... I don't know whether he had a breakdown, I don't know whether you'd call it that, but he certainly, I think, had a... freaked out. And that was mentioned - once again, you know, you're getting second-hand information - and it was his eyes that were mentioned then. So, I think it was... that's where he put his stuff. Other diabetics probably have other issues, but that was Tom's. He did go, when he was only fifteen - and he was, I suppose, relatively newly diabetic - and we went on holiday without him, and he went up to London to the National Youth Theatre to be a prop man, yeah, and scenery painter. And I remember that being a big deal. And I think that was really important. I think that was really brave of my parents, actually, because I'm trying to imagine doing it now with one of my kids, without diabetes. And, you know, so it was up by the train for an hour, from Crawley. He had to inject himself on the train, in the toilets, so what does that look like? You know, and he had to make sure he didn't... he wasn't on an underground train with no Mars bar, you know, and he was fifteen, you know. And I'm sure he was having a drink or two as well, at that time. So, that was important. I mean, I can still remember that's what he did that summer holiday. And I think that was probably... he probably got used to his diabetes without us, then. And you've asked the question, you know, about family and Tom, and we're talking about Tom and diabetes, and I think the two are separate, really. 'Cause Tom had his diabetes, it wasn't... We actually didn't sit down and talk about it, as a family, which sounds like a crass American thing to have done, but actually, that might have been quite a handy thing to have done.

So, how do you think the family was affected?

I think my Mum's felt guilty, and hasn't stopped. It hasn't debilitated her, but that was a crucial thing. I think that we were bound to have been... I think that there was probably some jealousy. I know that my older brother and Tom didn't get on very well with my older sister - they were closest in age - and that this didn't help. Jane can remember things I can't, as well. So, she was older, she was closer to it. She can remember him being ill, so she can remember him being ill, nobody doing anything about it, and something getting done. And him confiding in her that he couldn't walk up the stairs at school. He couldn't understand why he couldn't get up to the top flight, you know, which isn't far. And I remember that sort of thing is painful for Mum to hear, I think, you know. So, it affected different... you know, there's five of us, and, interestingly, the oldest and youngest in my family have got diabetes, and so they probably spoke the least about it, and knew the least about each others' lives. For, I think, for me, I think there was... I never felt like Tom got extra attention; I did think

he got different treatment. And I think that was it: I think he was allowed to express himself in ways that, maybe, we wouldn't have been allowed to. So, he did break things, he smashed things - he didn't smash people, but he did smash things.

(5) So, now can you talk about your younger sister's diagnosis?

Anna was diagnosed when she was sixteen, and she was initially diagnosed at school, by the nurse. Okay, it's a very weird thing this, because my Mum took great exception to it. She said... you know, we went back, she did another blood test, she wasn't... it didn't go the colour that it had gone. She went to the doctor, and no, she didn't have diabetes. And it was a very strange thing, because I remember Anna coming to me - I was at school with her, at the same school, so it was when I was still at home, and I was an A Level student - and she came and gave me a big cuddle, and said "I'm diabetic". And for her, it all made sense, because she thought she was diabetic from the age of thirteen, or something. She'd had it in her head. She'd kept some of Tom's urine sticks, and she... they'd got over that. Obviously, she obviously had it in her. And then, when I'd left and started my first year at university, she diagnosed herself. So, she did a urine test, it went black, and she was... I got 'phoned up at my sister's house in London, and she was diabetic. So, by this time, she was sixteen, doing A Levels - it was 1982 - I was eighteen at university in London. And I felt terrible, really, because, you know, you see, you can't feel terrible about something you don't know about, and you can once you know. And, of course, by this time, I'd seen my brother have hypos, and seen him rushed off in ambulances, and sat with him while he was horrible to people, because he was having a low blood sugar, and the rest of it. So, those anger things, funnily enough, now I think about it, that I'm saying he was allowed to be angry, could well have been low blood sugars that I wasn't... nobody explained to me exactly what it was about, so that's interesting. So, yeah, so Anna got it. And, you know, there's something about Anna that people like, and she, you know, she was a bit of a star in the hospital. I mean, it was the same hospital - it's now shut - it was the same hospital, but, you know, she was kind of the star of the ward. And things had changed, I think, but not wildly. My parents, of course, were much more educated about it. They probably knew what they wanted. But I remember Anna having a go at the doctors, telling them what's what, and where were they? and "I've been waiting for this". And she wouldn't take any rubbish, you know. And I think she... you know, it's horrible to think, it's like you all think you're adopted, at some point in your life. But to think you've got diabetes, you know, and then for that to come true, it must have been a... a double-edged sword isn't the right word for it, but it must have been "yes, I'm right, ha ha. Oh, God", you know, it's really what I've got to deal with. But she was a completely different... I think a) she's a girl, he's a boy, completely different way of treating the world, so that had an impact on it. Their bodies seemed to deal completely differently with it. And I think there was much more available to Anna, insulin-wise and education-wise and counselling-wise. So, she took all that, and she's dealt with it differently. And they've had... And she

has put it. . . I think, whereas Tom, it was at the front of his life, Anna has put it deep down, and to her cost, sometimes, I think, you know, health-wise.

(6) So, can you compare how diabetes has affected your brother and your sister?

I think that the most important thing, in their treatment of themselves, if you like, is that Tom has always - whether it's because of the eye thing, it might just be my take on it - but has always kept his sugars low, right on the edge, because, obviously, he's trying to protect his organs; that's - I guess - is the common understanding. So, he's kept his low, so subsequently he's had lots of hypos, more trips to hospital, lots of hypos with people around him. His has been much more on show, if you like, his diabetes. Whereas Anna, people often don't have a clue that she's got it. It's not to say that Tom walks around with it as a badge, it's just that the way he wants to live with it - or had for a long time, it's much more settled now - had for a long time, that's how it showed itself. He's much more of a worrier, and I'm sure you use up sugar when you're a worrier, as well. Anna's not, and she, you know, she went off to university, she did the whole thing full-on, and she's just that kind of person that didn't let 'it' get in her way. And I think that she's had some real ups and real downs; she's had some high blood sugars. I mean, I remember one time we were walking up the road, she got knocked over, as we were crossing the road. We got her to the hospital. She'd done something to her knee - which has still affected her today - but she was told off for having a high blood sugar. That's what they were concerned about, you know. So, it's an interesting thing, because I think you're a good person if you keep your blood sugars low, and you're a bad person if you keep them high. Those are, in the medical sort of fraternity, that's the way they see it. And I think Anna's pushed it down, pushed it down. And she's tried to take time, sometimes, to deal with it, but sometimes she hasn't given herself time. Whether that's a good or bad thing, I don't know. I said it was to the detriment because she said to me "oh, I've got to be more healthy", she said that to me herself. And I know that she's having some laser treatment on her eyes. But I don't know whether that's because of the way she's lived her life, or she's lived her life the way she has with it, because that's all she could do, because that's who she is, so. . .

What about your brother's eyes?

They seem to be fine, yeah. I mean, he's the worrier, the one who worried about his eyes. He's only just got glasses, only just in the last few years, just started to need glasses to read. So, he seems to be fine. I mean, he has been part of various projects, I think, a couple of projects, over the years, as well. So, he's definitely got into it, the science of it, if you like. So, he knows his stuff. And I think, for both of them, I don't know what the changes are, but every now and again they'll say "it's great, because there's this new stuff", or "I don't have to do it in the afternoon and the evening any more", or "I do do it three times a day, and that's much better for me". So, I think that the advances in medicine have improved both of their lives greatly.

- (7) Can you also compare how the family reacted to your brother's and sister's diabetes?

Well, I think, initially, we knew what it was, so we didn't have to go explaining to one another, and asking questions we thought... And that's difficult, for Anna, because we all just said "oh, it's diabetes". And I think we took her less seriously, and her diabetes less seriously, and, because of her very nature: "I can handle it", she's handling it - you know, she didn't show anyone any worries that she had, particularly - that all bought into it. So, there was a... I went to visit her, I did visit her quite often, and I was worried about her. But, whenever I saw her, she seemed like a much stronger person than me, much more together. I was in my first year at university, and I think I probably, you know, neglected her a bit. You know, we probably all didn't take her as seriously. And I know there was times when she actually sort of said, you know, "come and see me". And there was a time when she had to go back into hospital, when she'd moved from Crawley - my parents moved when she was in the sixth form to near Crowborough. She started a new school, Beacon - and she had to go into hospital, again. And I don't know why, what had happened there, to be honest; I don't know why. And I didn't visit her, then, and I think she felt really neglected by the whole family, including my Mum and Dad, at that time, I think. So, I think that was hard for her.

Can you talk about the effects on family life of your brother's diabetes, and your sister's diabetes?

I mean, obviously, it's about food. There's a huge part of this that's about food. And I don't, apart from that, you know, cream bun moment, I don't recall us having things taken away, saying "right, we're not going to have an apple pie for pudding, we're all going to have an apple". It didn't work like that. However, having said that, the family never had sweets in the house, sweet biscuits, sweet drinks, so there wasn't much sugar going on, if you like. And Mum cooked, all the time; nothing was ever frozen. So, it was probably a really healthy environment for a diabetic to be in. So, I do remember that Tom couldn't have sweets, though. And Anna and Tom, that was never a... I remember me and Anna ate loads of sweets, with our pocket money - partly, probably, because there wasn't sweets around the house, you know - but, so I remember she was a real sweet addict. And she had to immediately stop all that, obviously, and that didn't... To me, I don't think that was a huge blow, she was old enough to be able to do that. The only things that I remember were that, I think there were less chocolates bought, maybe, at special times, and you had to be more aware. And I know that, when we went out shopping when Tom initially had it, there was... you'd go to Boots, and you'd get diabetic chocolates, which were just like, you know, it's like alcohol-free lager, you know. Have a cup of tea instead; it's just not going to do it for you. So, you know, there was that around. I remember trying diabetic sweets, and, you know, you can remember the taste, now. It's pointless. So, I think that was obviously... that was associated with Tom. And it's funny, there was almost like all this lesson learned, by the time

Anna came along: well, we're not going to bother with that, we're not going to worry about that. And so, we were walking on eggshells with Tom, and we didn't take Anna, probably, seriously enough. We'd all left home, of course, so that's a different kind of impact, so it was really my parents and Anna. And I think the guilt associated with Tom, she didn't feel guilty with Anna. Maybe she thought - and this is not to be brutal - "not again, why me?" almost. Like, now, you know, "why have I got it twice?" my Mum probably thought, at that point. And I'm not talking about my Dad, because he's much less expressive a person. I mean, he's completely there, with my Mum, in all this, but my Mum does all the expression for both of them.

(8) Can you now talk about your next encounter with diabetes?

Well, it was roughly twenty years later. My friend's daughter was born in 1993, and she wasn't well, is the only way. . . I mean, she. . . I think she had meningitis. I know one should know that sort of thing, but she had something very bad when she was young. And then she had lots of strange. . . just lots of strange things; it didn't seem right. And even, like, as a visitor, I thought that. . . something wrong. And she went blue one day: had a fit, went blue. Got her to the hospital, and that started the ball rolling for tests. And it seems to me it took quite a while, but maybe it didn't take that long. They finally diagnosed her with diabetes. And, of course, it was very hard for her Mum, I think. I think, although things had changed, because I remember there was a unit, you know, there was a special diabetic doctor was associated, so she knew the name. They had lots of conversations about, you know, blood sugar test levels, you know. So, all that, that was all happening, and she was. . . I think the pastoral care of her daughter was much better than the care had been for my brother and sister - that had definitely changed. And the fact that. . . And what I realised, of course, was that the impact on the Mum never changes. She just felt the same as my Mum did: terrible. And I just was somebody she knew who'd had experience of diabetes. So, I think what she did was. . . she could actually have conversations with me about blood sugar levels, without me going "pardon, what?" or looking disinterested. I knew how important it was. I knew she'd spent months being up in the middle of the night, trying to raise. . . sending her daughter to bed, with slightly high blood sugar levels, and then in the night having to raise them again. I mean, just things like that. It doesn't sound much, but your whole life suddenly becomes, you know, five to seven, three to five - you know, numbers. And hers was numbers, and this was her daughter, a really little one that you couldn't explain very much to. So, I did feel terrible for her, and I could just listen, and I could say "guess what, my brother and sister are all grown and fine". That was a nice thing to be able to do, as well. And also, it was an interesting thing for me, personally, to be looking at it from the outside in, and seeing, you know, what was happening. 'Cause it, you know, it repeats itself, you know, the way food is talked about, and sugar is talked about, and injections and how to inject. Of course, that was all massively different. I mean, I'd seen it change with my sister and brother, over the years, but, luckily, my friend's daughter has never had to deal with. . . I mean, or my friend had to inject her daughter

with a massive long syringe, that would have been. . . . I can't even imagine it on little arms and legs. So, that was my next encounter, and I just really was there for her. And I think that got me thinking, later, a couple of years later, that - when I wanted to do some voluntary work - that I would get into that.

(9) Tell me about this voluntary work.

I decided I wanted to do some voluntary work, and the Diabetic Association - I think that's what it was called then - was looking for volunteers for their helpline. So, I threw myself into that; did the whole course, and I actually really enjoyed doing that. I wasn't there very long, because of my own personal reasons - my life was changing radically, and I wasn't any use to anyone else, I didn't think, at the time. But it was very interesting for me to learn everything that I felt I knew about. So, I knew about it all on the receiving end, if you like, and suddenly I was learning about it from the scientific point of view, and what you can say, and what people can do. And reading articles on it, and articles that didn't really seem to know more, sometimes, than they did when my brother got diagnosed. I think that was the thing: once I immersed myself in it, I realised how difficult it was for Tom and Anna to get a straight answer, because they got very frustrated over the years - different doctors, different insulins, different methodologies, completely different attitudes to it. And that's because nobody has a very clear answer about this. And I remember taking a really upsetting call from a girlfriend of a bloke who had not looked after himself. You know, it's hard enough to just look after yourself anyway, sometimes, but had not looked after. . . . And he was really trying, now, okay, and she was a part of that. And he just couldn't. . . . it just wasn't making any difference to him; his blood sugars kept going up. And I felt completely useless, and I think the hard thing was that there wasn't a straight answer. You can just do your best, and try and keep your blood sugars down. And I think the other thing was that even people who had managed to keep them down, still might have, you know, lost. . . . something wrong with their foot, or they're losing their eyesight. And I think that was the upsetting thing. You know, it was good to be there for people, but at the same time, the lack of answers was quite incredible, really.

Tell me a bit more about how this helpline was organised.

Well, we - the volunteers, without any medical experience - were trained to deal with people on the phone, learnt the basics of diabetes, and so they knew what to expect on the phone. Once it got to a point where we didn't know what they were talking about, on the phone, we had the nurse there. So, the nurse was always in the room when we took the calls. But we could supply basic information, point them at the right things, send them information in the post, and reassure them, I suppose. That's partly it, just having somebody to pick up the phone, initially. And then we would take the problem, if there was one, to go further, to the nurse, and she would deal with it. So, it wasn't. . . . we weren't left alone to make up our own minds about people, tell them what to do on the other end of the phone, but we were part of a system that was set up to be a support system for people with diabetes.

(10) And tell me a bit more about your training for the helpline.

Well, most of it was pretty dry, sitting in a class, and then there was some role play. And then there was the day trip to a hospital in South London - which suddenly escapes my mind - where there was a foot clinic, essentially, run by this one woman, who was just one of those amazing people you find, working with no... clearly in, you know, the NHS, with no money, and doing miracles. And having a good relationship with all her patients, who were, on the whole, poor, ordinary people who hadn't been able to, or encouraged to, or hadn't looked after themselves well enough, so that their feet were falling apart. And, you know, some of the sights I saw there were just, I mean, stunning. People with nails in their foot, but didn't know that they were in there. I remember her digging around at a hole in someone's foot, and scraping the bone with the scalpel that she had, you know. I mean, I think I was so - I don't like going to the dentist - but I was so gripped by it, and her - the way she handled it, and the decency, but the way she got on with it - that it was an education, that day. And it was also... it was a side of diabetes I hadn't seen, because I think Anna and Tom were born into, not a family with very much money, but a middle class family that had... that went in search of information. And they too went in search of information - ways to look after yourself. And I think, even though they've had periods of not looking after themselves, if you like, they'd never had the sustained, you know, lack of attention. Other people were just old, older - too old to have known that they had diabetes, and so had lived with it and lived with it. And their bodies had... the blood sugars had done the damage on their bodies. And that was the... that's just a day I won't forget, really.

(11) And can you talk about the attitudes to diabetes that you encountered while you worked on this helpline?

Well, it's interesting, because we're talking about comparisons between when my brother got it, and later. And you would have thought things had changed - and things have obviously changed - but there were some attitudes that remained the same. This is '96, '97. And there... I remember one lesson we had, where a diabetic midwife came to educate us about diabetes in babies, or parents with diabetes who had babies, and they were larger, and this sort of thing. And I just remember being so cross, at the end of it, because essentially, what she'd done was, she'd given us a lesson on good and bad diabetics, as though, once you're a diabetic, those are your two options, you're not a person anymore. So, you know, she showed us babies that were huge and ill when they were born, and this was the mother's fault. And gave us an example of a mother that she'd told off - and she told me that quite proudly, told the class that quite proudly. And I just felt so cross with her. I mean, I had a four year old, didn't I - yes - at this time, you know, so I'd been through what it was like to have a baby. And you get told off, having a baby, anyway, let alone being told off for having a baby and, you know, not having your blood sugars perfect. It was awful. And I mentioned before, when my sister got her knee pranged, and actually, she went out without a crutch, but she needed one. But she had been told off about her

diabetic, you know, her levels of sugar. And that's a conversation I've had with Tom and Anna, over the years, about how they feel like they're somehow on trial, you know, when they go to see the doctors. And when they get a good one, they don't want to lose them, because you have to... If there's any illness that's about the whole person, it's got to be diabetes, because you're integral to keeping yourself alive, aren't you? So, you know, without you, you're dead. So, I think it's pretty stupid to not take the whole person on board, and say "this person's going to live their life, and they've got to be able to live with diabetes, not because of it". And my brother's got... his son has become diabetic since... as a teenager, as well. And I know Tom, now, is on this - if I call it a crusade, he'll have a go at me - but every time he goes in with Jed, anywhere, about this, he's on the case, you know. He's not there to badger the doctors, but often he knows more, and that's okay. It's like when you're pregnant, you really do know more than the doctor does, and that should be okay with the medical profession. It should be okay to learn from your patients, I think. And that might still be yet to come, I fancy.

So, you mean that your brother's determined that his son shouldn't be told he's a bad diabetic?

Yeah. I mean, he'll... he's... When he and his wife go in with Jed, there's no hiding stuff from Jed, there's no patronising. He won't accept it, and there's none of this talk about, you know, "are you being a good boy or a bad boy?" It's just not a relevant thing. It's, you know, how can you get through this without it changing your life, or making your life impossible to live? And that's what Tom's, you know, all about. He won't let... he doesn't want Jed to think of himself as a good or a bad person, because of the way his diabetes is, you know, showing itself.

What about the kind of feeling special? You said your brother, when he was diagnosed, felt special. How has he dealt with his son?

Jed's an only boy... an only child, rather, so that must be completely different. He's got a father who's a diabetic, and is very kind of... talks in a way where it's all boxed off, and all that stuff. So, I think that he's not going to get special treatment from Tom, you know, he's not... And his Mum is a very practical American. Her sister's got it - she's got diabetes, her sister - so she's very practical, straightforward. And I don't... I think they probably couldn't have handled it better. If you wanted an example of... Maybe that's what you need: you need to have been a diabetic, you need for your sister to have been a diabetic, and then you'll be fine with your kid, I don't know. I think they've used all the tools that they could have to make Jed feel like he's okay. He's got this, he can go on, he's no more important than anyone else, but there's something he has to think about extra in his life.

- (12) Now, thirty four years on from your older brother's diagnosis, you know two children with diabetes: your friend's daughter and your nephew. Would you like to reflect on that?

Well, they're both fourteen. Obviously, she's had it a lot longer than he has. I think that their lives are easier with diabetes now, as a teenager, compared with Tom's, because they've got the pen and not the great big syringe, they've got fancy machines for your blood sugar levels. People are much more involved at the... there's more of a pastoral care element to it, I think, and just children are different, you know, they're going to speak their minds. They're both complete sweethearts, you wouldn't know it was there. They are different. I mean, I know that I've seen my friend's daughter have much, many more sweet things, in her life, than Jed does, and that will reflect my brother's attitude to it, now I think of it, about the low blood sugar thing, and my friend's attitude to it, which is obviously different. They're both well, happy, lovely, and I think that they've probably benefited from, you know, the recent changes in attitude, which have still got to change. But I think that my friend, she wasn't... I mean, I think that she's probably had a harder time having such a young kid get it, and also not knowing anyone, except a friend, who had any connection with it, whereas my brother had been steeped in it for thirty years, by the time... you know, forty years by the time his son came around with it. So, it's a different world for them, and I think that they'll probably take it more in their stride than Tom and Anna had to.

(13) And then, there's just one more person in your life who's had diabetes, so can you talk about that?

Yeah, that would be Margaret, my mother-in-law. So, that's Type 2 diabetes. And I met her in '96, '97, and she'd had diabetes and not been diagnosed with it, like a number of people, I think, in Scotland, particularly. It's been about her diet, her weight; I think that's why she got it. And she was initially on tablets, and she would... her husband looked after it all, actually, and I think she struggled... What was interesting, if you like to say interesting, but I talked to her about it, and she would do the things she was told to do. You know, she was very much "the doctor said do it", you know, working class woman, Dundee, the doctor says that you do it, that was kind of what she did. So, she would have the baked potato, and then forget and have a great big ice-cream. You know, there's partly, you know, she did what she was told, but she'd lived for seventy years before she was given this information, and I think it's incredibly hard to change your lifestyle, at that age, whatever it is you're now living with. So, she and her husband, who did all her blood tests and gave her all the tablets - he was like in charge, in a nice way, you know, just in a caring way. But it was always an issue when we went to see them that her... she couldn't control the levels, and it was always going to go and see the doctor, the diabetic doctor again, until they then put her on insulin, eventually, and that really helped her. As far as I can tell, her life got better. It wasn't awful at all, it was just better with insulin. And, you know, she didn't talk about it. She did just... she definitely ran her life, and food intake around it, though.

Would she have realised that she was disobeying the doctor's orders by having ice-cream?

Do you know what? She's not stupid, but I don't think she did. I really don't think she... I think 'cause she thought it would all balance out, yeah. And I think... it does, it makes me sound like I'm describing her as an idiot, and she wasn't. She was really, you know, bright and great, but I think that... I don't know, I like to think, in a way - this might be strange - that she did it on purpose, just to say "I don't care. I want an ice-cream, and I'm seventy six, whatever, so I'm going to have one", you know. So, I think there was an element of that: you know, this is who I am and this is what I like. Apparently, according to Craig, she used to eat a box of chocolates every day, so that's, you know, that's where she was coming from, so it's quite hard to get her to stop. But in the end, her eyes went, so in the last year of her life, she started to lose her eyesight. And she pretended, a little bit, that she didn't, but, you know, she definitely was losing her eyesight. The last time we saw her, she couldn't really see people so much, so it was a lot of listening, and faking it and that, and then, you know, after that she died.

- (14) So, your mother-in-law had Type 2 diabetes for about ten years, from 1996-ish. Can you talk about living with Type 2 diabetes for ten years?

I mean, I think the thing that initially I was thinking was that when you've lived your life a certain way, then to have to change it like that, I think it just doesn't compute. And I don't think... I think that must be the hard thing for young doctors, if you like, to sort of say that "this is the plan. It's okay, it's quite clear, and if you manage your life like this, it will all be fine, and here's the tablets". But I think for Margaret, there was a cupboard full of pills, and there was all these measurements to live by, all the right foodstuffs to have, the wrong foodstuffs to have, and that right and wrong thing again. And I think she partly didn't... I think partly she didn't want to do it, and that's why she gave it to her husband to deal with, and partly, you know, she just didn't want to think about it either. You know, she wanted to just... I don't think she really ever maybe came to terms with the fact she had it. And I think that's partly, like we spoke about, she broke the rules. Even though she was very careful about her lunch, then it would be later on that she broke it. I think that's quite an interesting way she dealt with it. But I think she was... I think it shortened her life, and I think, probably, she'd had it a lot longer than any of us knew, any of her family knew, and so it had probably done the damage to her eyes, because she'd obviously had the tests regularly, and then suddenly, it suddenly happened. And I think she... and she was never angry. She was kind, generous, very liberal - you know, her children live across the world, and she doesn't have expectations of them at all. She's not judgemental, she's very kind, and she... you know, you live your own life, and you don't comment on anyone else's, is kind of her thing. But I did see her, you know, in the last year really angry, because she felt like they weren't... they said they weren't going to operate on her, because, I think, they just... there wasn't an answer, once again. It wouldn't have... they weren't deliberately leaving her to slowly go blind, but that's what she was doing. And I think that she just wasn't prepared to live without her eyesight. I mean, that's... I'm not a crazy spiritual person, but I think that she just

thought “no”, because we all, you know - being the young groovy people we are - we sent her up mini-discs, and we sent her up tape players and Walkmans, and all that stuff, talking books. She loved reading, and it wasn’t because the stories were good, it wasn’t just that. She loved to read, you know, to sit with a book, and that’s a very different thing to having a set of earphones on your ears. So, I do think that Margaret objected greatly, really, deep down to having diabetes at all. And I think that Type 2 diabetes is a sort of... comments on your lifestyle, doesn’t it. It says you got this because you’ve behaved like this in your life. And, you know, it’s bad enough being told off when you’re a teenager. Being told off when you’re seventy is completely out of order. So, I think when she lost her eyesight, and realised it wasn’t going to change, she just said “no, I’m not going to live without my eyesight”, so she didn’t.

But the people that you’ve known longest with diabetes are obviously your older brother and your younger sister. Any more reflections on their diabetes?

I think you put a figure on it: Tom’s had it for thirty-something years, and that’s a long time to live with diabetes, I think. So, he’s doing quite well, and I think that he has changed, as a person, in his attitude towards it, as well. I don’t think he lets it dominate him as much as he used to. I don’t think you can have children, and let something like that dominate, so that’s changed him. And Anna’s sort of come the other way: allowed it to come into her life a bit more, you know. I still hear from my Mum, worrying about Anna. So, I think that the two of them have handled it completely differently. I think that there’s an interesting thing to be said about how boys and girls deal with such a thing in their lives. And there’s something to be said about the way they are treated as people, and not patients. Because, once you get something that’s with you forever, it has to be not something that will be seen to go away, so you have to take the whole person. And I think that, you know, slowly and surely, Anna and Tom have developed their own way of letting people know it’s part of them, but it doesn’t run them.