

57. Gillian McGuinness

(1) Tell me about your background.

Well, I went to a direct grant independent school, because it was my parents' big ambition to move out from the working classes, and I was lucky enough to pass. It was fee paying, and my parents worked very hard to get me there. I went right through to A levels there, and finished in 1973. I wanted to do science, and that's what I managed to do at university. I was the first child of my family to go to university, so that was a major thing in 1974, and chose to go to read human physiology. I would have liked to have done medicine, but now, I realise, it was very much out of my grasp. I mean, the A levels I needed, I didn't quite make. And I think with a different background, I may well have re-sat, but I didn't. And I did human physiology, which was based in the Medical School in Manchester. When I finished that, I thought "what am I going to do with this science"? It was very much human science I wanted to do; it was very much human contact. I rejected the idea of going into laboratories or anything like that. And at that time, there was a dire shortage of dietitians. And somebody in the year above me was going through the process of becoming a dietitian, or entering further training, and I thought "that sounds as though it might just fill the gap". It coincided with me getting married, the two, three months after I graduated in 1977. So, I started my eighteen months Diploma of Dietetics newly married, much to the disgust of the tutor, who was out and out a maiden dietitian, and finished there after eighteen months, and started my career.

Was that course at Manchester too?

Yes, it was at Manchester. It was run by a place that we call Hollings College, but was basically the polytechnic, or became the polytechnic, and now, I believe, is part of Manchester University; certainly the Metropolitan branch. But it had to be Manchester, because that's where I'd settled, because I was married. And my husband was a bank clerk, so we didn't have much opportunity to move or live anywhere else. And there was good hospitals there, which was another reason to stay in Manchester.

You said that the woman who ran the diploma course was very much a "maiden dietitian". What impression did you get of the world of dietitians, as it was, when you first started training?

It was very much an evolving world. Training, that I went through, with a diploma, was fairly new. There was, I think, probably one or two places where you could do a four year degree course. I mean, that's the one thing: dietitians have always had to be graduates; well, since the seventies, sort of thing. The lady I'm talking about had stepped out of hospital medicine, and had been sort of coerced into running an education programme, and was quite good at it. But she was entering, sort of, the last phase of her professional life, and had obviously spent all her time working in hospitals; very dedicated. Very much like the nurses of the day were, really. Fifties trained, and dedicated to hospital work.

(2) In the seventies, there was still a heavy catering involvement. I think, up until then, dietitians had either been nurses, who'd sort of got an interest in the nutrition side, and therefore the catering establishment, or they were caterers - hospital catering staff, managers - who became more interested in the clinical side. And, if I think back, a lot of the qualified dietitians, at the time, probably did come through the ranks of home economics and things. But, in the seventies, there was a lot of sort of medical advancement, and there were a fair few disciplines evolving. Renal was one: very specialist dietetic care for renal; obviously diabetes; a little bit on tube feeding and intravenous feeding. But the science was starting to come through, and that's what attracted me, rather than just, sort of, the hands-on catering. But, I must admit, when I went into the hospitals, I was still heavily involved with the catering side. I had to liaise with them a lot more than I do now.

Can you remember what you were taught about diabetes during your training?

Well, I was taught the rudiments of diet therapy for diabetes, which, in many ways, are still the same. The bedrock's still the same, in as much as it's a problem with metabolism of carbohydrates. And, therefore, the treatment, at the time, was to restrict carbohydrate. Obviously there were lots of insulins around, but compared to what we've got today, very limited in their action. And, therefore, most people were on twice-daily injections, and therefore the diet had to fit round the injections. So, basically, it was carbohydrate - I would like to call it restriction. It was carbohydrate allowance, but by very nature of being allowance, it actually did restrict.

(3) Can you go into more detail of that, for the historical record?

Well, yes. I mean, I was taught - and anybody in the late seventies, probably very early eighties - was taught carbohydrate counting, in as much as we used exchanges. So, everything was equated to - usually - a ten gram carbohydrate exchange. Some people did function on fifteen gram carbohydrate exchanges, but, on the whole, it was ten grams. And we were very rigorous in what equated to ten grams, to the point it was, you know, two thirds of a slice of bread. We had free foods, which obviously tended to be the fats and the sort of more salad sort of vegetables. And we were trained to give an allowance. Now, sometimes that was prescribed by the doctors, but in children, which is obviously where I ended up, in children we were encouraged to give a carbohydrate allowance dependent on their age. And then we would split that over the course of the day into meals and snacks, and a bedtime snack. So, it was three meals and three snacks. We tried to fit it into how they ate, but that was how I was taught - textbook - which was basically a hundred grams of carbohydrate for the child, plus ten grams for every age. So, a child of seven would have a hundred and seventy grams of carbohydrate, and that would be split between three meals and three snacks. So, something like, I suppose, four exchanges at meals, and probably two between, if that adds up to a hundred and seventy; but that sort of thing. And if the child was hungry - well, I didn't even think about that in

college. I just thought, well, that's what they do.

Was it always on the basis of age, rather than size, that you varied the amount?

Always on age, and equally for adults. That, obviously, wasn't on age, because once you've finished growing, that isn't so important. But there was a set amount, and there was no way that that was going to change. Obviously, if they were a bit more... in a labour intensive job, we would allow them - because you'd ask them - we'd allow them a little bit more food, and probably a bit more at snack time. But, on the whole, it was very set amounts, and they just had to sort of get on with it. We gave them, obviously, a diet sheet, and we gave them a carbohydrate counting guide. And that was basically how I did it. I mean, I remember I did assignments and, you know, worked out these diets for workmen and things like that, and you just said "well, that's it, you know. You'll have six exchanges for your breakfast, and like it or lump it, really".

- (4) Well, on the table in front of us, you've got a booklet called "Carbohydrate Countdown" (see Extras). How does that illustrate the approach?

Carbohydrate Countdown was a whole series of literature and aids to help people count carbohydrate - usually alphabetically; later it became sort of colour coded - where you could look and see how much carbohydrate's in your Weetabix, and decide how many Weetabix you could have that would contribute to your six exchanges for breakfast. The Carbohydrate Countdown didn't actually work in exchanges, I think. It tended to work in grams of carbohydrate, but ten grams of carbohydrate was an exchange. So, they had to be fairly numerate, but they soon sort of got a little guide - probably encouraged them to write their own guides of food they ate, and what would constitute ten grams of carbohydrate. The carbohydrate exchanges, I never questioned, practically, until I actually got working with patients. It was just, very much, a numerical thing. Each food item or drink, or anything that had carbohydrate in, just got a value: one, two, one and a half, whatever. And you would make up your numbers to match your daily allowance. Obviously, there were foods that were free, as I've already mentioned, but there were also foods that were absolutely not allowed, and that would be things that would have very high carbohydrate content. So, obviously, sweetened things and sweet drinks, sugar itself; anything that was considered very sweet. Let's see: sweets, chocolate. Because, at the time, people were encouraged to have fructose to sweeten things - and you could actually buy fructose over the counter - rather than sweeten with sucrose, which the population at large were doing. There was no mention about fat; we took no concern about fat. It was just purely carbohydrate exchanges, and making sure they got not too many, really. I wonder, sometimes, whether we actually focussed on whether they got enough. And there were lots of ways of guiding people. But the practical side, obviously - as most students - I didn't actually think about until I got to deal with patients, and then I realised that this wasn't quite so simple.

And during your training, did you also come across the approach of counting these ten gram portions?

Well, definitely, the ten gram portions, because to me, from 1979 onwards, they were exchanges. I mean up until that, prior college, I hadn't realised it. But obviously the background to these ten grams carbohydrate exchanges was the precursor to all of this, which was the Lawrence line diet with black and red lines, where the black lines were carbohydrate, equating to about ten grams of carbohydrate, but I think given more a value of the calories that ten grams of carbohydrate would consist of. So, obviously, the diet was worked out on the total energy requirements of an individual, and then split down into how many red and black lines. So, what I experienced - because that was history, when I arrived - what I experienced was the new thing of ten gram carbohydrate exchanges, which, to this day, still provide forty grams of energy. But we don't actually - or we didn't, at that time - look at the total amount of calories. We just used that once to calculate their exchanges, and let them get on with it. But, obviously, if they ate a lot of fat, then their calorie level went up. And if they didn't eat the right amount of carbohydrate then they were going hypo. So, it wasn't ideal; it was very restrictive.

(5) What kinds of people with diabetes did you see during your training?

Well, I was obviously training in Manchester, and, as I said, there were lots of big hospitals in Manchester, so that was a very good basis for training. Predominantly adults, because, obviously, that's where most people with diabetes are: in adulthood. But there were two children's hospitals: Booth Hall, and a very small one - the Duchess of York - which was in the south of Manchester. And I certainly saw children there, but I only saw them; I didn't treat them. I just knew that these children - poor children - had got diabetes. But I was also very aware, at the time, that children with diabetes went to special schools, and were treated as delicate children, and were not encouraged to mix with the general childhood population. They were just starting to attend ordinary schools, but a lot did go to special schools. I don't know what the incidence was; I just know I did see the odd one. There was a large general hospital in Manchester, where I eventually did work, and they did have a children's ward - a very mixed children's ward - and, of course, occasionally, we did get a child with diabetes on that ward. But, in my student days, I probably didn't see very many children. I know I did a case study for diabetes for a gentleman, who was in his early thirties, and had had diabetes since he was seventeen. And he did address some of the adolescent issues. And because he was older than me, at the time, and he was talking about what it was like to be seventeen, I felt very much in the middle, and did identify with some of his issues: with the restrictions, and how it stopped him doing things, and how he rebelled. And how, at the age of thirty two, he wished he'd not rebelled quite so much.

Then tell me about what you did after you completed your training.

Well, I started work, I think, in early '79. All of the hospitals where I had been training - I was very fortunate - there were jobs available, which meant we didn't have to relocate or travel long distances. And I started in a hospital, which now, actually, has gone - Withington Hospital - which had been one of the old original

workhouses, with long Nightingale wards. And I started as a basic grade. There were, I think, four basic grade dietitians, and we sort of worked alongside senior dietitians; each of who had got specialities, and, of course, one of the specialities was diabetes. So, I rotated round in the year and a half I was there, and went through the different disciplines. And with the girl who did diabetes, I did do diabetes clinics, but it would only be for adults. And I certainly saw people with diabetes on the ward. We did get new people with diabetes, but, on the whole, it tended to be people admitted with issues, and they happened to have diabetes. And we would be going in to help them, because, obviously, they'd got to order special diets from the kitchen, we had to make sure they get snacks. We often went to continue, or even begin their education, for some of them, because I felt some had probably never accessed a dietitian, or hadn't done for many years. But we had to make sure they got the right food. All diabetic diets were sent up special from the kitchen, and we had to order them every day, relevant to the exchange value of the meal they needed. So, if somebody came in and said, "well, I need a six exchange lunch", then we had to make sure a six exchange lunch came up. There was no question that anybody would portion anything out for them on the ward. It was a case of it arrived plated, and that's what they had. If they were hungry, well, that was it. If they couldn't eat it all, they'd just got to eat it all! I'm not sure whether they did, but that was it. We just meant to make sure they'd got plenty of drinks that were sugar-free, or water, and that they had got some snack foods, and that they were getting what they felt that they required. And that's when I did start to realise that diabetes was a very interesting subject, because it wasn't just a case of dietary manipulation; there was all sorts of other issues going on. And, obviously, there were advances in insulin starting to arrive in the very late seventies, early eighties. And, although I didn't see any children, I started to become quite interested in diabetes then. And then I very quickly moved, still within Manchester, but just across. Again, to another teaching hospital, but one that had this children's ward. And that's when I came across children with diabetes, because, on a Friday afternoon, there was a general children's clinic, from a general paediatrician. And children with diabetes would arrive, newly diagnosed -

- (6) by casualty, obviously - but eventually would find themselves into his clinic. And we never knew what we were going to see. But these children with diabetes would arrive, having had a stay on the children's ward, where we would have instigated their diet education: given them diet sheets and exchange lists, and worked out how much carbohydrate we thought they needed for their age, and sent them on their way. In fact, taught them everything we thought they needed to know, in just over a week, because that's what the children had to do. Probably a week to ten days, they were taught everything, from injections to food, to the future. And we just saw them in outpatients when they came.

And what was the role of parents?

Parents did everything - parents and carers - because it was fairly complicated,

really. I mean, I did spend a lot. . . I do remember going to see children on the ward, because, obviously, parents weren't there all the time. And I'd go and see them, and have a little chat with them, and sort of try to introduce education ideas to them. But most of the. . . well, all of the literature was for adults. There was very little that was geared up for children. And I would just sort of go and revisit the kids, and make sure they understood that, you know, they weren't to just accept sweets off people, and they did need to make sure they had sort of sugar-free pop, and things like that. And that, if they were hungry, could they wait till it was snack time? And if they were hungry before a meal, could they wait till it was mealtime? If they were very hungry, then yes, we would increase the carbohydrate exchanges numbers at meals and snacks, but, on the whole, we'd encourage them to try and keep within that. But most of the education was to parents, with the children in the background, but, I mean, the information was all for parents. Thinking about some of the children that I saw: obviously the ward staff would alert us to any situations, where they thought the children weren't happy with what they were eating, and then we would go and see them. That was the very nature of how the dietetics worked: we had to have patients referred to us, or issues referred to us. But once the children were our patients, then, obviously, we called on them most days. And, occasionally, there'd be times when they would say "I'm just so hungry". And we accepted that, because, obviously, when you start insulin - even today - when you start insulin, you can be incredibly hungry, and your appetite is enhanced. But we were reluctant, or not encouraged, to send more carbohydrate. And, if I think about it, we used to have a way of ordering foods that would, perhaps, fill them up, but wouldn't contribute to their carbohydrate exchange allowance. So, we would. . . the kitchen would happily send them boiled eggs and pieces of cheese, and slices of meat, along with salad things. But they could have those if they were very, very hungry, alongside some of their carbohydrate snacks, perhaps; certainly at supper time, at bedtime, when they might be hungry. And I just thought that was okay; that's what we did. But, obviously, you're sending higher protein, higher fat foods, and keeping the carbohydrate very limited.

(7) And what are your memories of adults with diabetes, during those years - '79 to '83?

Well, predominantly they were what we used to call Type 2. So, they were possibly insulin-requiring, but, on the whole, we would start them off with some weight management, because - as today - the majority of them were overweight. Then they would start on some tablets, and then, if necessary, they would go onto insulin. It was very much a weight management situation: just total restriction in calories, trying to control some weight, and hopefully control some blood sugars. I don't remember them being actively encouraged to do blood tests, because, of course, we're talking pre the days of any meters, any automated blood testing. We're actually pre days of disposable syringes. For the children, we'd just about started using disposable syringes, but, prior to that, they were syringes that were glass and had to be boiled to sterilise. And, if they wanted disposable syringes, the families had to buy them. And many families did, but

there was no means... support to buy them. They had to sort of... parents' group used to establish means of getting them in bulk, and then parents would come and buy them in box loads when they came to clinic. So, blood testing was very difficult. Blood testing was very much like a chemistry set, where you used to have different coloured solutions and different tablets, and put them in and dissolve them, and add a little drop of your wee, and see if you'd got any blood sugars or ketones. Blood testing... Urine sugars or ketones. Blood testing was just not possible, unless it was in a clinic or a hospital environment. So, on the whole, adults were Type 2; weight issues; they didn't know what their blood sugars were; they would do some wee tests. And we just did our best with big, big clinics. I mean, they were clinics that were full, then. So, I don't know what the incidence of childhood diabetes was then, but I know my experience was predominantly Type 2 in adults. We would get the odd one that was Type 1 - which was insulin-dependent - and they were, on the whole, very lean. Not surprising, because we were carbohydrate restricting them. They were very lean, and often had some... the beginnings of some complications. I mean, that was my experience of diabetes, then, that you were going to get complications.

What are your memories of these big, big clinics? Just visualise one.

Well, just as they are now, really. Wall to

- (8) wall people, in varying degrees of mobility and complications. I mean, it was just accepted that it was a norm. A lot of people had foot problems, and a lot of people had mobility problems, often because of their weight, sometimes because of neuropathy. And a lot were very fearful of that. So, you know, the newly diagnosed were very keen to try and get their diabetes as controlled as they could. That's as much as I remember, really.

Was there always a dietitian present at a diabetes clinic?

Where I worked, there would have been. But that doesn't mean to say she saw anything like a reasonable percentage of the children - or the patients, generally, if it was an adult one - because the numbers were too big. But that's the same now; the numbers are too big. People have to - or had to, and still do - have to elect to see a dietitian. She would certainly be there, and the clinician may well ask for her opinion, but, on the whole, the majority would go without seeing anybody.

Can you remember what the attitude of you and your colleagues was to these overweight adults?

I was always very sympathetic, really. It was very difficult, and still is, to get any success with these people, because we go back to days where there was no food labelling on the backs of packets. People did tend to make more things for themselves, but there was certainly plenty of easy meals around. But they had no notion of what was in the foods they were eating. And, therefore, to actually cut down for them was quite difficult, unless we gave a very prescriptive routine to eat to. Obviously Weight Watchers was around, at the time, and

it was basically calorie restriction. And the answer was, if a thousand calories doesn't work, you take them lower. And we knew that didn't work. But, on the whole, I was very sympathetic; certainly the ones with diabetes, because I knew their prognosis for complications was not good.

(9) What did you do after you left the Manchester hospitals?

Well, I stayed in Manchester. I left the Manchester hospitals to have my first son, and, in those days, there was no such thing as maternity rights. And I agreed that if I had a live child, I would not be going back to work. It was a choice of going back full-time or not at all, so I agreed I wouldn't go back. And basically had, probably, about six or eight months at home with him. And then I got a 'phone call - as a contact from the Manchester hospitals - but a 'phone call from somebody trying to set up some dietetic service to BUPA hospitals, which was a private health company, just to provide any sort of dietetic input. They'd obviously got a very strong catering base, and they'd obviously got clinicians and surgeons who would come to do their private work. What they hadn't got was, at that time, was allied health professionals, and were looking for me for a base of dietetics. But I presume they did the same for physios and everything. I mean, some consultants did come with their favourite team members in tow. But obviously there was a gap for dietetics, so I was recruited to give a weekly service. But it was only one day a week, to several of the BUPA hospitals in the North West. And my job was sort of to liaise with the catering staff, to make sure they were up to speed on any requirements they were asked to provide by the clinicians or the nursing staff, in dietetic-wise, and to train them if they felt they needed training. And also to run some outpatient clinics of people, who had perhaps been referred by clinicians and surgeons, to see somebody who was dietetically trained. So, on the whole, it was weight reduction and high fibre. Weight reduction pre-surgery, and high fibre if it was any sort of bowel complications. Occasionally a little bit on diabetes, but really very general. And I commuted round the North West, on a weekly basis, for probably about four years. I don't think I did any locums whilst I was in Manchester, because we very quickly moved down to Bristol, which coincided with me having my second child, in 1985. And BUPA just transferred me from Manchester hospitals to Bristol hospitals. So, I carried on doing the same sort of role in the Bristol hospital, which was fairly new - a new BUPA hospital there - again liaising with matron and catering staff, and making sure they were up to speed. And doing any outpatient work that any referrals from surgeons and clinicians might have been. But, because I'd got a foothold in Bristol, and that was our home, I did do some locum work at Bristol Royal Infirmary. And I did some research work for Bristol, as well. I did a little bit of antenatal work there, and antenatal work with the diabetic people, or gestational diabetes, and a bit of outpatient work for them. But really not a lot of clinical work, really, until I relocated back towards the north - back to the Midlands - in 1989, which coincided with getting my second child to school, and thinking "right, what do I do now?".

Just before we move you to the Midlands. Can you remember, from your contact



with women with diabetes who were pregnant, was there quite a good expectation for them then?

Women who were pregnant: yes, there was. I never saw, or even was aware of what happened to them, pre-conception, which is unlike today. We'd encourage them to go to pre-conception clinics. But once they were diagnosed, yes, they were very looked after. The biggest fear was large babies. I would have been very surprised to hear of any problems with the outcome, but then I wasn't around at the outcome. The expectation was that they would deliver. And, to be fair, they were very, very highly motivated, and actually their diabetes was probably the best it had ever been controlled; quite rightly so. And many of them were Type 1s on insulin, with a lot more aggressive therapy. But some were obviously gestational, and were put straight onto insulin, to manage their diabetes, during pregnancy, as well as could be expected. And, as far as I'm aware, they were encouraged to believe in a normal outcome.

(10) And tell me what happened after you left Bristol.

Well, as I said, we relocated to the Midlands, and I got my children settled in school, so the youngest started school. And I did think I would have a few months thinking what to do next. I never relinquished my registration; I always paid that. And lo and behold, an advert appeared for two sessions a week - seven hours - at Birmingham Children's Hospital, which, for me, living thirteen miles out of Birmingham, felt manageable, but fairly scary, because I'd never driven into Birmingham. And I wasn't even sure it was going to be worth it. But off I applied, and I got offered an interview, and off I went. And I did quite like the environment, was pleased to be back in and looking at it, and being considered for it. The Children's Hospital, at the time - the diabetes unit - was stand-alone; autonomous. And they were recruiting a member of staff that would fit into their team. We were working alongside two nurses, who I think, at the time, were called Diabetes Nurse Specialists. They were certainly paediatrically trained nurses, and were working exclusively with diabetes. The consultant was very, very keen on diet for his children. I think that was helped by the fact that he'd got a dietitian for a daughter, and he realised that food was very important in the management of children with diabetes. And I think I just fitted the bill, in that I was available for the two sessions, I'd got two young children, and I had got some experience of diabetes. Not a lot of paediatrics - I think my paediatric experience came because I was the mother of two small children. And I was offered the job there and then. But the journey to Birmingham was so horrendous, I had to think about it for a weekend. And then decided "look, if I'm going to keep with the profession I'm trained to do, I really ought to do that". And I thought it was a nice avenue. I really didn't want to go into just weight management, which was what a lot of part-time work was offered. And I didn't want full-time - I wanted to be with the children - so to me, it fulfilled my needs. It did coincide with me applying for another job, locally, which was nothing to do with how I'd been trained, but actually did, eventually, overlap with my work as... in dietetics, because I applied to be a registrar of births,

marriages and deaths, in Solihull. And that was part-time, also. And that was offered just after the Children's Hospital, and I managed to run the two together. But it was quite interesting, because, obviously, I worked... I did some locum work in Solihull - although my main work was in Birmingham, I did some local work in Solihull, locum - and, obviously, came across patients in antenatal who, eventually, were registering the births of their children. And they weren't quite sure why they'd seen me twice. But, I must admit - going back to gestational diabetes - I was quite shocked, one day, when somebody that I knew, who I'd been looking after and advising in the... as a locum in the antenatal diabetes clinic, who was proceeding through her pregnancy fairly well. Obviously, I left as locum, but in my job as registrar, I saw that they'd been in to register a stillbirth, at term. And the cause of death was... cause of foetal death was maternal diabetes, and I thought that was really quite sad.

(11) What was it like at the Children's Hospital, when you first arrived?

Well, as I said, we were working in a small unit - diabetes home care unit - and we were quite unique, at the time, because we were offering home management. So, for me, it was a little bit of a steep learning curve, because we were now not hospitalising children at diagnosis, unless they were particularly medically unwell. We were out in the community doing home visits, and a lot of home education. Obviously, it was exclusively children, so there were no Type 2s, at the time. Obviously, no weight issues: just getting children through their growth and their development. And also, we were starting to move away - this was 1990 - we were moving away, or had moved away, from, exclusively, exchanges. They were still around; they were still around in lots of parts of the country. We had them, we were still using diet sheets with exchanges on, but we were introducing, at the same time, a bit of a healthy eating concept. But, I certainly taught exchanges to - in the first couple of years - to the children who we had then. I, as I said, I only did two sessions a week, but I was working alongside another dietitian, who was working part-time. So, we were probably about a point-seven of a dietitian, working with the children. And we had, probably then, about three hundred children that we looked after. The problem with Birmingham Children's Hospital is that the catchment wasn't clear, in as much as GPs were able to refer from all sorts of areas. And we had to be very careful that we did sort of visit within a... no more than a ten mile radius, otherwise we would have been travelling long distances. But, yeah, they were happy days. We were out and about, teaching, visiting schools, running grandparent days and just education days. But, on the whole, we managed the children at home, if they were well. We used to just introduce ourselves at diagnosis, in casualty - a very brief exchange, very basic information given - and then the nurses would be out visiting at injection time for the next two or three days. And we would join them and start their dietary education, which, like I said, was exchanges, with a little bit of healthy eating slant.

(12) What was it like for the families after diagnosis?

Well, as it still is: devastating. But for me, that was the first time I realised just

how devastating it was, because, obviously, I was returning to work with children, and I'd got my own children. And I realised that the diagnosis of diabetes is a very big diagnosis. And soon after I'd started at the Children's, I remember attending a sort of a conference, where teams were invited. So, we went with a doctor and a nurse and a dietitian, and then they mixed the teams, so we ended up with doctors and nurses who we weren't used to working with. And we were given scenarios of what it was like to break the diagnosis to somebody. And I remember a consultant, I think from Scotland, saying that he felt the diagnosis of diabetes, at the time, was harder to give than diagnosis of leukaemia. Because leukaemia had an outcome, had good prognosis, and you either had it or you didn't, and you would get better or you wouldn't, whereas diabetes was a long, chronic condition for the rest of their lives. And many, many parents - and still do - grieve the loss of their healthy child. Although the child is fine, and is running round and looks fine, their life changes at diagnosis. And, of course, a lot of parents come with experiences of their own of diabetes. Not necessarily their own personal ones, but their family and friends. And, at the time, they were very frightened, because they knew it affected life expectancy, and they knew complications. They just knew, if you've got diabetes, you're more likely to have your leg off, or whatever. And we, you know, we had to work long and hard to make sure that they realised their children could have long and happy lives. At the time, they were going to mainstream schools. We were encouraging schools to provide the right sort of school meals and snacks and environments for them, and we were happy to support the parents for that. So, we tried to paint a very optimistic picture, because it was, compared to what I'd been trained. But, the impact really hit me that this is a major thing, because you have got to inject your child twice a day for the rest of its life. And parents used to worry, even when the child was quite small, about young adult issues, and would they have children, and all these sort of things. And, to this day, they still do. But, obviously, there's a lot more information available now, on the internet and things. But, back in the early eighties, there wasn't. And a lot of the information that was written was American information, and still very much adult based. So, we did have a lot of work to do, to create, sort of, paediatric information.

You said the eighties - but in 1990, was there much literature?

Right. 1990, it was probably starting to come. I mean, the drug companies that produced a lot of the literature, still focussed very much on adults. There were schemes and awards to create children's information. I know we created quite a lot of our own, and used our own. And then you would liaise with other hospitals to see what they were creating. A lot of them just expected the children to manage with diet sheets that were really adult diet sheets. They just gave the very basic information. But the information was going to adults, anyway; it was going to the parents. In those early nineties, we weren't addressing the children so much, until they got a little bit older, and perhaps we'd have them back for an education day when they were changing school, or something like that. At diagnosis, it was very much to the adults: this is how you're going to have to

look after a child with diabetes. But, I think that reflects the education system at the time, really, that you just... this is what you do.

(13) What were the main changes during the 1990s?

I think the main changes was the relaxation down in diet for diabetes. We moved away from exchanges, and went to what we called healthy eating, which, for those of us that had been trained with exchanges, always worried us, because healthy eating is different things to different people. And I always kept a notion of where carbohydrate was, and what carbohydrate did, and what I... was considered to be good, and sort of not so good carbohydrate, and encouraging the children not to overeat. The main thing was still to control their weight and their blood sugars, because, at this time, we were seeing the first blood testing machines available. They were quite large; they took at least four minutes. You had to sample the blood and time it, and then wipe it off the sensor before you actually put it into the machine. But, they were revolutionary, in as much as they did actually give a number, whereas before, it was... When I first started, in the nineties, we were still using BM strips, and they were comparing colours. And it depended on how good the person viewing it decided what colour they were. And then, it only gave a range of blood sugars. I can't remember the ranges now, but, you know, it was something like the range of 3.5 to 7.5, and then a range of 7.5 to 12.5. You didn't actually know what your blood sugars were; you just knew you were in a range. And we were still urine testing. So, the diet had relaxed slightly, because, in the population at large, we were now more aware of high fibre, the F-Plan, Rosemary Conley was starting to become popular. So, people were aware of quality of what they were eating, rather than just quantity. And it was in that vein that we started to develop, sort of, healthy eating approach, which was basically, as long as you avoid very high, very fast carbohydrates, then you can pretty much have whatever you want. Our concern always was, you're still reliant on two injections a day, same amount of insulin going in every day, so how can you vary that so much on what you eat? And I think the general feeling was that, provided they're eating to appetite, then the children won't be eating that much of a variation on a day-to-day basis. We started to look at fat content, encouraging them to eat more carbohydrate, if it meant they would eat less fat. And that was a big change... difference to exchanges, where exchanges we didn't really bother... we didn't even

(14) think about how much fat they were having. But, again, it was all in an environment of awareness of heart disease, and effect of lipids of diabetes and things. So, if I think about it, it was healthy eating: avoiding very high carbohydrate - very fast carbohydrate - foods; avoid very high fat things; maintaining enough carbohydrate, enough energy, for growth. Because that was a big issue, when I'd first started training - although, I hadn't realised it - that children, in the late sixties, seventies, and probably even into the eighties, often were not growing to full height potential. Whereas in the nineties, by then we'd sort of got... we must get enough energy in to make sure they grow well, because there is enough insulin around in

the population at large: we can give them insulin if they require it. And children were growing quite well. We used to measure them and plot them on growth charts, and make sure they were getting enough calories to grow, and that their blood sugars were okay. We used to always make sure the blood sugars were around ten. We were never looking for very, very tight control, because if we... we found that if we got very tight control, then the children were soon getting very hypo. And then having to treat hypoglycaemic reactions with high sugar foods, and then that would affect the blood sugars. So, the aim was to keep their blood sugars a little bit higher than what we might call the norm - what we might want now - in an attempt at getting them to eat well, and have a normal life, really.

So, you were taking into account, now, their size, as well as their age?

Very much so, because we weren't giving an allocation of exchanges dependent on their age. What I would do is, obviously meet them and interview them, and ask how they normally eat. And, in a totally non-judgemental way, if that seemed to be okay, if they were not overweight - and I had to take into account what their weight was a long time pre-diagnosis, because, obviously, they lose weight at diagnosis. And most parents would present their child saying "oh, they've lost lots of weight", but actually they were ideal weight. My aim was to keep them an ideal weight, rather than let them go back to being overweight. So, if they looked all right, and they'd no weight issues, and they could give me a reasonable routine of how they had been eating in the past, then I'd let them go with that, having removed high sources of refined sugars. So, we had sort of a five point plan, where we'd sort of say "avoid very high sugary things; make sure you get sugar-free drinks; eat carbohydrate at every meal and snack, but make sure it's sort of long-lasting carbohydrate; avoid sweets

(15) and chocolate; and don't buy specialist diabetic products. Up until, certainly starting at the Children's Hospital, diabetic products were being used, and I hadn't actually thought you shouldn't use them, really. I mean, there was move in the dietetic circles, generally, to try to stop prescribing them. But, certainly when I got there in 1990, you know, I was saying "if you need things, then have ordinary food. Don't go and buy specialist diabetic products". So, yes, they were fed to their appetite. If they gained excessive weight, which, invariably, some would, then we would look at: one, the quantity of food they were eating; and two, the amount of insulin they were being given. Because, obviously, they go hand in hand, and we used to have to bring one down first. So, often, we'd bring the food down, and tell them to adjust their insulin, dependent on what their sugars were. Sometimes, you might just say, "look, the insulin's far too much, bring the insulin down", and then alter the food. But, on the whole, it was food first, which was why the consultant was very keen to have a dietitian on his team.

Why did you advise against specialist diabetic products?

Well, specialist diabetic products, obviously, had had a role many years before. I think, partly, because we were encouraging more fructose; there was no nutritional information on the backs of packets of ordinary food. We stopped recommending them because they were often of no nutritional benefit, because, if you reduce the carbohydrate in a custard cream, then you presumably put the percentage of something else up, and it tended to be fat. And, by the very nature of being labelled “suitable for diabetes”, people were going out and eating a whole packet of them, because they thought “if a little’s good, a lot’ll be better”. So, we... And they were very expensive. And, of course, the other thing was, they were sweetened with sorbitol. And sorbitol was known to have a laxative effect; had a warning to that effect on the back of the packet. But, if they weren’t alerted to it, the children would happily go and eat a whole packet of, I don’t know, humbugs, or a bar of chocolate, and then find that they’d got upset tummies, and soon learned not to have a whole packet. So, what with sweeteners that sort of lost favour, cost, the need to buy special products - the idea that “I can only eat a custard cream if it’s a diabetic one” - they sort of lost favour. And I think the ones that exist even now, nearly twenty years later, tend to be sweets: things like humbugs and the odd chocolate, which tend to be bought, now, by the older Type 2, who probably shouldn’t be eating high calorie sweets anyway. Because what people think is, “they’re suitable for diabetes, so they must be sugar-free, which means they must be low calorie”. And they’re not. So, we still say “don’t have them”. There’s still a lot of calories in

- (16) things that are suitable for diabetes. And, of course, new sweeteners came around. So, the general population had drinks - fizzy drinks, cordials - available to them, that were now suitable for diabetes, because of the bulk sweeteners. I mean, when I started in 1990, we’d only got saccharin. And then we got the advent of all the other sweeteners, which produced very good products, so we said “go and use the products that are available to the general population at large”. In fact, we encouraged families that everybody would use these products, and then the children didn’t think that they were different in any way.

You mentioned earlier that you, and some of your colleagues, who’d been trained before that, were a little bit wary of this phrase “healthy eating”, because it meant different things to different people. Can you expand on that?

Well, healthy eating is a quality issue - it doesn’t address quantity in any way. And, the problem with just saying “healthy eating” is that some people will still have weight issues or blood sugar issues, because they’re eating an awful lot of something that they perceive to be good. So, I think we always tried to put a bit of a quantity slant on our quality eating. I know we were quite unique in this, at times, because there was a little bit of research done to see what general diet information was being given. And I think the general consensus was, at least half of the dietitians in the country were giving out a mixture of quality and quantity advice. Some of the younger and newer-trained ones were just doing quality, and there were still some stalwarts that were just doing quantity, which

was exchanges. But we tried to sort of sit in the middle, and always explained to parents and children what a portion of food should be. And still do, because that's part of the population problem, at the moment, is that everything is sort of super sized, and people don't know what a portion of food should be.

And do you still differ from younger dietitians, who might think just of healthy eating in terms of quality?

Well, no, because the younger ones are coming through now, having... the world realising that you... we need to look at carbohydrate again. And, with the new... advent of new insulins, we're coming on to carbohydrate counting, which isn't carbohydrate exchanges that I was brought up with, but it is an acknowledgement that carbohydrate needs to be measured, and then the insulin's given to match that. So, the very newly trained will have some notion of that. The ones - because I was talking to someone only yesterday - who were trained probably about ten years ago, so the sort of middle nineties, have very little notion of quantity of carbohydrate, and are having to learn it themselves, just like they're having to teach their patients, with the new insulins and the new insulin regimes. And they're having to realise where carbohydrate is. Whereas, those of us professionals and patients who have a notion of where carbohydrate is, and what exchanges were, it's not quite so difficult for them.

(17) So, have dietitians come full circle, then, from sort of portion counting to modern carbohydrate counting?

No, I don't think they have. A lot of people think that. A lot of doctors, who've been around as long as I have, also think that, but, once you explain it to them, no we haven't. If we go back to healthy eating, which was basically very much quality, it became very aware, alongside healthy eating and carbohydrate exchanges in the background, that amounts of carbohydrate had different effects on blood sugars. And so, again in the nineties, the notion of glycaemic index became very popular, which was a measure of how quickly a carbohydrate could be absorbed and enter into the bloodstream, with glucose being the highest - obviously very quickly absorbed. And then all foods being given a rating, relevant to how quickly glucose was absorbed. And it became very obvious that how food was prepared influenced how available the glucose was. And so, for example, a potato, whether it be chipped and fried, or boiled or mashed or jacket, would have a different glycaemic index, depending on its availability to the body. So, it became blatantly obvious that, if you took an amount: a potato, giving so many grams of carbohydrate - you could call it exchanges if you wanted to - actually, depending on what was done to it, was available to the body in different ways. And from that, then we sort of bolted that on to the back of healthy eating, and started to teach a bit of, sort of, quality and quantity of carbohydrate. And some people, you know, still focus very much on the glycaemic index. Because glycaemic index became very popular in the population at large, knowing that, if you concentrate on foods that have a low glycaemic index, and therefore won't cause major fluctuations in your blood sugars, then obviously your insulin needs are less, and you don't get hungry so

quickly. So, it worked very well with general population and diabetes education, and probably coincided with advent of new insulins.

(18) Did parents and children understand the notion of glycaemic index?

I think parents always understood that blood sugars varied, depending on what the children ate. Even those who may still be doing a little bit of measuring would realise that a meal with, for example, spaghetti - spaghetti bolognese - would always affect the blood sugars differently to sausage and mash, or something like that. And yes, it could be explained by glycaemic index, but the whole notion for us... We didn't teach it exclusively to the parents. They realised that there was a quality of carbohydrate, but we still focussed on just, sort of, healthy eating, with this notion that some sugars will lift the... some foods will lift the blood sugars a lot quicker than others. But it all started becoming a bit more important when we were... started to move away from twice-daily insulins - again with the advent of more variety of insulins - and we started to introduce, what they called, basal-bolus, which was giving some insulin with food eaten. We didn't actually do any measurements of food, at the time; we weren't actually counting carbohydrate. They just gave doses at times of eating. But, it was still very limited, because we'd only got insulins with fairly short lives, and that goes right up till 2000, really. And then, into the 2000s, new insulins arrived on the scene, which were able to give a long-acting background of insulin. And then, what they married to that - the drug companies - the suggestion was if we have a long-acting base insulin, then we are now able to give short-acting bursts of insulin to coincide with meals. And if we need to know how much insulin we give, we need to know how much we're eating. Therefore, we need to be able to count carbohydrate, and give amount of insulin to match the food eaten - the carbohydrate eaten - at each meal. And, therefore, we come to carbohydrate counting, which is totally different. Because the person, the individual, the child, or whatever, can eat, in effect, whatever they want to eat at a meal, carbohydrate-wise. They would count it - and we teach them, again in amounts... usually about ten grams - they would count it, and then they would give insulin to match that, depending on the carbohydrate insulin ratio that we have decided for them. On the whole, it's usually a unit of insulin for ten grams of carbohydrate, but, depending on the age of the child,

(19) we might vary that, depending on time of... since diagnosis. Certainly at times of rapid growth, we would certainly end up giving them more insulin for amount of carbohydrate, because, obviously, their needs are much greater for insulin. And that has liberated diabetes thinking. Unfortunately, it's very slow to transfer people over from twice - children, especially - from twice-daily insulins to multiple daily insulins, because, obviously, it means a lot more injections. But the ones who do it are well aware that it gives them a lot more flexibility of life. On the whole, we've seen better blood sugars. And we've even seen a lot better weight management, because now the children are no longer just taking insulin to control blood sugars: eating what they want; more insulin, because the blood sugars are going



up; more appetite... increased; eating more. Now we've got them so that they actually eat what they want to eat, and have insulin to cover it. But now, I'm back to teaching where your carbohydrate is, and how to count it, alongside healthy eating. What I don't want them to do is to not have carbohydrate, because then they wouldn't... they feel they wouldn't need insulin, and eat a meal that is very high fat, high protein. I have to encourage them to eat some carbohydrate, so that they get the nourishment they need, but they will need to take insulin with that. We now, in 2007, are starting all our children - regardless of what age they are - on multiple daily injections. Which means, right from diagnosis, they are back counting carbohydrate, and have to have an understanding of where carbohydrate is, and, therefore, how much insulin they're going to have to have with each meal.

You say they have to have an understanding of it. What happens if they don't?

It's just part... Same as if they didn't have their insulin. They have to, because they have to have insulin to match the food they eat. If somebody really, really struggled... But, I mean, we give them information. They can soon - a bit like the information when we gave the original carbohydrate countdown and exchanges, if we go back the thirty years - they get a little chart that says "if you have a bowl of Weetabix, you need so much insulin; if you have a glass of milk, you need so much insulin", and then you add the two together, and that's what you give for your breakfast. If they really can't add it up - and there, again, we're back to having some maths. The amount of maths involved, now, does worry me considerably, because I know the population at large is not that numerate. When you start talking about carbohydrate ratios to insulin doses, to how many grams of carbohydrate,

(20) you have to have an understanding of your maths. But, if they really can't cope, we would probably introduce them on what we call a 'set dose'. So, we'd probably give them, say, "you've got to have four units with each of your meals", or something like that, and see how they go. But that, unfortunately, clips the benefit of the regime that they're put on to. But, for some, that's how it is. And in the adult sector, for several years now, probably for all of the 2000s, there's been a system called "DAFNE", which is Dose Adjustment For Normalised Eating. And they run education programmes for adults: adults who want to be able to modify their insulin dose, depending on what they eat. My only criticism for DAFNE is that it doesn't consider healthy eating at all. It has not accepted that as part of its remit. So, for some people, it gives them carte blanche to eat whatever they want, and just take insulin for it. So, they could eat, you know, a kilogram of chocolate, and just take insulin to cover it. Whereas, for others, they still keep to the principles of diabetes, but it just gives them a bit more flexibility. They don't have to get up at a set time to have their twice-daily insulin, and they don't have to eat when nobody else is eating. They can eat out with their friends later, because they take

insulin to match what they eat. So, yes, we are now back to teaching where carbohydrate is - but I never stopped, and I'm sure most dietitians have had to taught where the carbohydrate is - but how much is there, and back down to what a portion is. Because, although information's on the back of packets, the portion that Mr Kellogg says a bowl of cornflakes is, may not be the size of bowl of cornflakes I eat, or you eat. And the kids have to understand that that's fine, but they may need to take twice, or three times the amount of insulin that they would imagine they need, from reading the information on the back of a packet. The biggest problem for carbohydrate counting, I think, really, are the professionals. I mean, the doctors do find it very, very difficult, because everything you eat, you've got to think "how much insulin would I need for this?". The one good thing is, with the insulins that are around at the moment, the children and young people, and adults, can eat and then inject - which, for the first time in their lives, means that they are able to leave food and it not influence their blood sugars. Or, even, eat more food and it not influence their blood sugars, because they can take more insulin to match what they've eaten. And, I imagine, with the advent of more, sort of, chemical engineering, and what they can do with insulin, then the way we manage diabetes will change. But, at the moment, that's where we are. And, even with the new devices - the inhaled insulins, and things like that - we are still down to carbohydrate counting, because the insulin has to be given to match the food. And the ultimate, which is a pump - an insulin pump - more than ever, you need to have an understanding of where your carbohydrate is, and the effect of it on your blood sugars. Because you actually tell your pump your carbohydrate to dose ratio, and how much insulin to give, because you've eaten a certain meal. So, carbohydrate counting is actually right at the middle of diabetes management, again.

- (21) How do families, for whom English is a second language, cope with this complexity?

People ask me that a lot; people who haven't got experience of a multicultural environment, where they live. On the whole, they do exceptionally well, because what we try to do is be aware of the foods they would want to eat, and give them a measure for how much insulin that might require. The beauty of people who... of families - who are usually, for us, Asian background - are, they are still very much a family unit. And they still eat as families, and they have a very limited choice of foods. So, they tend to have chapattis, or possibly some rice, at meals... at both meals. And they will eat a very simple breakfast, which is often an egg and some toast or some cereal. They tend to drink water, for the children; possibly some milk. So, we will go through the sort of foods they would normally eat, and give them a measure - just like we'd do for anybody - and give them a measure. I have cut things out of magazines, and given them little ready reckoners that way. I've been... I obviously go to their homes, so I can do it. And I was at a home only yesterday, where somebody made me a chapatti to show me the size of chapatti she makes. And, as soon as I say to her "yes, that's

going to take two units of insulin”, then she’s quite happy that, you know, as a Mum, she’ll do that. For me, we’ve got a lot of multicultural issues, because we work in a very large city. And that does bring its issues, because, obviously, we’ve got more Type 2 diabetes arriving in overweight children. But with the population - the South Asian population - generally having more Type 2, in the adult population, we’re also seeing that coming through into their children; certainly the children that are overweight. It’s a thing that we’re seeing across the country at large. But we do have, now, one or two children who are definitely Type 2s - of both Caucasian and Asian background, but predominantly Asian - and who are overweight. And they are classic Type 2s, and they need managing as Type 2s. The first thing I need to do is sort of normalise their eating, control their weight. And they’re insulin-insensitive, so we have to make sure they get some tablets. And often they’ll start on insulin, because the main thing is to try and protect them from any complications. So, those diet issues are a bit more difficult. But, the first thing is to try and get them to lose some weight, and take out some of the fried foods they might have, and things like that.

How successful are you?

Type 2 is a very difficult condition to manage, not least because, as a cultural thing, people see Type 2 as the ‘mild’ form of diabetes. And even though they’re looking at a child of perhaps nine or ten with Type 2, they still see it as the mild form, and we have to say “no, it isn’t”. Very difficult, and, I think, probably the tip of the iceberg.

(22) Is that a major change, since 1990?

Well, in 1990 - I remember vividly - the incidence of childhood diabetes being told to me, when I went out to schools and things, was one in six hundred children: that was of Type 1. We’re now saying it’s one in three hundred school children. And that’s in less than twenty years. In 1990, we had no Type 2 children, and in... now, we’ve probably - we’ve not got a lot - we’ve probably got about 20%... no, 5%, probably - 5% of our population have got Type 2 as children. But also, we’re seeing other things. Because now, the NICE guidelines - the National Institute of Clinical Excellence - gives guidelines on how we manage diabetes. And we also, because of that, we now screen for other autoimmune conditions. So, we routinely screen for coeliac disease, and we screen for thyroid. Now, when I first started in 1990, we would only pick up somebody with coeliac disease and diabetes - of which it obviously is much greater risk of getting the two, once you’ve got one - we’d only pick them up if they were failing to thrive, literally. Children that were just not getting back to full nutrition, having been diagnosed with diabetes. And I do remember, vividly, the first girl that happened. A little tiny three year old, who was so thin; skeletal. And then we diagnosed coeliac disease, and she blossomed. But she’d been diagnosed with diabetes, so her weight loss... people just thought that was what it was. But now we screen them, and we’re picking them up at diagnosis. Picked up two this week, at their original diagnosis. Bloods have come through, and they are highly likely to have coeliac disease. But they have to go through, obviously, the diagnosis for coeliac

disease, which is jejunal biopsy. But we're now getting an awful lot of kids who are diabetes with coeliac disease, so we've got double dietary information, there. And, of course, working where I work, we're getting a lot of children who have diabetes secondary to other major conditions; perhaps children who are on anti-rejection drugs and steroids. Children with cystic fibrosis are living a lot longer. We've got quite a large tranche of children who've got cystic fibrosis and diabetes. We've got children with transplants, who've also got diabetes; leukaemics, who developed diabetes because of their treatment. So, obviously, my experience of diabetes has changed a lot since 1990. But the majority, for me, is still Type 1, if we want to call it Type 1. We're trying to find different names for it now. But children who arrive acutely unwell, for a fairly short time, and

- (23) diagnosed with diabetes. I'm afraid to say, we still get them who've just gone to the GP because they've got a boil, or an infection, or they're a little bit tired, and the GP sends them away with antibiotics. And then they go back to the GP two days later, sicker, and eventually come to us with diabetes, having just been diagnosed. It should be a fairly swift process; it isn't always. But obviously, once it's diagnosed, there's only one way, and that's insulin and watching what you eat, and get on with it, really. But also, we've got kids who are growing very well, doing exceptionally well, achieving major physical feats: Duke of Edinburgh Gold, and playing County sports, and even National sports. So, when I look at what it was like in 1990, where the prognosis of a normal life was not quite so good. And actually, thirty years ago, girls were almost advised not to get pregnant, really. Now we say "you can do most things". And to come full circle, I did attend a DAFNE course last week. And in that course was meeting people who have been diagnosed thirty years, who were diagnosed at twelve, and are still very well into their forties. And it was interesting to see the spectrum of people: some who'd been keeping to exchanges, in some form or other, for the last thirty years, and were not prepared to change. They just knew "this is what I eat", and they were perfectly controlled. Where you get the others who have gone, what they consider, healthy eating, and have gained lots of weight, don't really understand how diabetes works, and they also have got issues. And some who've got complications, and that's why they've come to learn more about their diabetes. So, I did see the whole spectrum of the types of dietetic management I've seen over the thirty years, and realised that each of it's had its values. The one we've got at the moment, I think, makes for much more comfortable lifestyle, much better lifestyle for the children, whatever culture they come from. The main problem being, though, is that the multiple daily injections mean they've got to have injections at school, with their school lunch, and presumably with any snacks they might have. And, therefore, now I find myself going back into schools a lot more, and encouraging staff to support the children, and school dinner ladies, and teachers, and things like that.

With these increases in numbers, are you able to do as much home visiting and school visiting as you did when you started in 1990?

Well, it's a very interesting comment. It's a very hot topic, that, because

(24) in the age of audit and governance, and things, we've been looking at our figures for quite a long time. And we've been well aware that it's been a very extravagant way of managing children. The parents that have that sort of treatment - the home visits and twenty four hour access to nurses, and contact with the team, generally - truly value it. And, obviously, we're very reluctant to give it up. But in the NHS, being as it is, I mean, it's quite a luxury to be able to visit people in their own home, and to be out on the road. And it looks - I returned after annual leave last week - it looks as though we're going to totally change the way we work, in as much... offer home support at diagnosis; offer home, you know, treatment at diagnosis. But then encourage the individuals to access us, by bringing them back into the hospital on a day case, or to meet up with us. Still have phone contact; still go and see them once a year; still do annual reviews - all the things we normally did - but perhaps getting them to come to access us a little bit more. I think we've gone... we have been very patriarchal, very supportive, in the last twenty years. And it's not quite fitting in with the sort of cash-stripped NHS, and possibly a little bit disempowering. Family life has changed a lot. People are used to accessing their own information - they access the information off the internet and things. So, the motivated families will come and access the information from us. And those that, perhaps, aren't so motivated, will still have telephone contact, and we will address any issues that they develop. But, it's just become too expensive. One of our biggest problems is poor attendance in outpatients, which, again, is very expensive. But that can also be equated to: well, they know that we'll still see them if they don't come to outpatients. So, perhaps we need to be a little bit more hard, perhaps, and make them take responsibility for their own conditions, and that of their children. On the whole, it works. We just hope we don't lose too many - fall through the net. We've still got a population of - in our hospital - of just over four hundred children with diabetes. And, of course, we discharge them all between sixteen and eighteen years of age, so ours is a rolling population all the time. Whereas the adult sector, they've got clinics of thousands and thousands of Type 2s.

(25) You seem to be accepting that the loss of home visits is inevitable. What are the pros and cons of home visits?

Home visits are a privilege. A privilege for the professional, because you go out into the home, and you see how they live, you can access food in cupboards. And they can relax and show you things in their home environment. A privilege for the individual, parents and families, for some of the points I've just raised, but also because they are more relaxed, the childcare arrangements for other children are managed, because the children are there with us, and they haven't

got the expense of getting to the hospital - the time expense, the money expense. So, for them, it has been a privilege. But then, family life's changed. In 1990, there were an awful lot of Mums who were still at home, and you could access them during the day, or towards the end of school day, when you might see the children as well. And what's happened, over the years, is we find it's harder and harder to access families during the day, even if we do just want to see parents, rather than just seeing the child. And then you've got to be very careful that, parents will often invite us to go, but the child isn't available. And we're aware that we'd rather be there when the child is there - certainly when the child gets to sort of seven or eight, sort of thing. They need to be there to understand we're talking about their diabetes. But it's very difficult, sometimes, to make the individual child - and families, sometimes - but certainly the child realise that they do blood sugars for themselves, not for us; that the numbers are important for them, not for us. And I wouldn't like to think that they were going to sort of just give us the story that they feel we want. For those that have never had home visits, then they will not miss them. And I must admit, there are times when you think "would I really want people coming into my house twice a year, just to sort of go through a tick sheet of how things are going? Things that I might well have talked to them on the 'phone the day before, or seen them in clinic two months before". I think, just the world, at large, has changed, and perhaps people do want to access their own information. We are still available, we will always be available. It might free up some time to do more education in schools, because, like I said, the incidence of school children is increasing. So, it may be better to educate people who will access them at school: school nurses, and things like that. We will still... we run an extended drop-in service at the weekend, so families who think they've got a problem can just call it. And we will run more, sort of, study sessions and group sessions during school holidays, and possibly when they come to clinic, to make the clinic experience a longer, more productive experience. So, we've got finite personnel, we've got finite costs, so it's a case of just trying to create a service that is the benefit of the parents and the children, but within the cost restraints. And who knows, you know, it may change. But at the moment, with traffic, you know, you can find yourself out on the road for a lot of the time, for very little patient contact. And in the NHS of today, that isn't productive.

(26) Can you now talk me through the different ages of children that you see, and what their particular problems are?

Well, that's the joy of working in paediatrics. I mean, the needs, and the way you access the children, varies depending on what age they are. Thankfully, we don't see very many very small babies. Probably, we see many under two, even under one, but by then they are, from my viewpoint, eating normal food. If they are very small babies - and I have experienced two or three in my time - and they're still being bottle or breast-fed, then we tend to just encourage them to bottle and breast-feed, and would blood test after they've fed to make sure that their blood sugars are coming up high enough after they've fed. Obviously, if it's a food you can count the carbohydrate of, then you're half way there. But

you never know how much they're eating, and that does make it very fearful for Mums who are breast feeding. But we tend to encourage them that there are ways around it. Obviously they have to use dilute insulins, and we have a, sort of, a ratio of insulin we'd start them on, depending on their body weight. And we just get on with sort of feeding them, and bring them through to weaning. Many might be diagnosed - not many - but some are diagnosed at weaning, probably six, seven months, and you would introduce them into small amounts of carbohydrate. Probably start weaning on non-carbohydrate foods, really: things like vegetable purees and things, with very little carbohydrate in, and then get them up to amounts of five and ten grams of carbohydrate quite quickly. And eventually onto baby rice and things, and get them into a carbohydrate distribution throughout the day. We haven't actually started any young baby, or young child under two, yet, on a multiple daily injection regime, but we will be doing, so we'll see how that goes. And then the next phase is really sort of pre-school. The hardest time, probably, for the pre-school is - people like to call it the terrible twos, or the toddlers - where feeding can become very erratic. And obviously, we do need regular food for these children: one, to make them grow, and two, to make sure they get good control. And, again, going onto multiple daily injections will help this, because, obviously, if the child doesn't eat, it won't need any insulin. But I do worry about the effect that will have on the child's approach to food - meaning that, if they eat, they get an injection, and if they don't eat, they don't. But we'll wait and see what that comes out. I mean, I have been worried about that for a long time, when they were on twice-daily

- (27) insulins, and, you know, giving a set dose before they eat. And some professionals would say "well, give them the dose after they've eaten", and I always used to say "no, we've got to make sure that they do get some insulin, regardless of whether they've eaten or not, otherwise they'll know that it's either injection or no injection". If it's one unit or two, it doesn't make any difference to them. It's the fact that it's an injection or not an injection. So, we'll see about that. I haven't actually dealt with that age group, yet, on a multiple daily regime. The next issue, really, comes to school, and when they're sort of sharing foods, and being a bit more influenced by their peers and television. And realise, perhaps, that they shouldn't eat sweets that are given out at school for good work and things - and we talk to teachers about that - and things that are taken for birthday parties. And encourage them to bring food home, or to show Mum, before they eat lollies that are provided at school, and things. But, on the whole, that age group do okay. Bit of erratic exercise. We sometimes find that they can have unexplained hypos, or things that need treating, because they've just had a spurt of activity. Or the opposite, you know, they sort of suddenly just spend all afternoon lying on the settee watching television. But, on the whole, they're fine, because they're still influenced very much by their parents. The parents are responsible for the food they give the children. They may not be responsible for what they eat, but they are responsible for the food they put down in front of them. So, on

the whole, with the right information to the parents, then the children do quite well. And we do encourage the parents to treat the whole family in the same way, to stop any, sort of, any more inter-sibling rivalry than you have already in a family. I suppose the hardest time starts to come at adolescence, and... well, if we start early adolescence, when they change school. Very difficult time to be diagnosed. A time of major change in their life: more independence; altered body image, generally; growing; lots of other hormones around. And that is a difficult time to manage, and to be diagnosed. If they'd been diagnosed before that, we tend to see... have a study day, and make sure that the child, itself, knows what's happening with diabetes, rather than it just being "this is what my Mum tells me to do". But if they're diagnosed at that time, it's very easy for parents to sort of say "well, you're eleven, you know, you can cope with this". And we spend a lot of time saying to parents "no, they can't. They can't cope with it". They may want to be independent one minute, but they also are very dependent in others. But that's where they are in their development, anyway. You've got to make sure that you are there to support them, because their aim, at that age, is to please. But they don't always do what you want them to do, so they'll find a way of making it look as though they're doing what you want them to do. And then

- (28) things present in clinic, you know, where it's obvious that they'd not had insulin and things. So, we encourage parents to support the child, and encourage the child to let the parents support them, right the way through, really, but certainly once they get to secondary school. And then, I suppose, the next difficult stage is adolescence - as it is, as it exists - so that can be any time from eleven to eighteen, depending on how the child develops. But certainly around fifteen, sixteen: major issues about wanting to be like your friends. And having diabetes does impact on every part of that, whether it be going out, eating your MacDonald's with your friends, or staying out late, or having sleep-overs, learning to drive, relationships, sport, homework, exams. All that will influence their diabetic control, and obviously the way they eat and manage their lives. And we tend to know that children with diabetes do have an altered attitude to food, because they've been told they've got to do it. So, for some, it means they will eat when they're not hungry, because they've always been told to eat, and others, they will gain more weight than they want to gain. And there is an element of concern for those that realise that, if they get very poor diabetic control, and run very high blood sugars, then they will lose weight, producing ketones. So, that, then, manifests itself as a bit of a weight-control issue, and they're manipulating their diabetes to do that. So, we've got to sort of address how we can help them with their weight, and not just poorly control their diabetes. But the multiple daily injection regime should help that, and it has, in our experience, to date. But that is a difficult time for them. And going right through to leaving home, and going to university and college, or just starting in the world



of work: that's another difficult time. But, at the end of the day, I think if they are fairly well adjusted and have grown well, and are fairly well nourished, I feel we've sort of a job well done. Because, if I go back to when I first started, they didn't grow very well, and they didn't get full employment opportunities, and they weren't encouraged to marry and have children. So, we have come full circle. But every age needs revisiting, because, obviously, the needs of the children change on a monthly basis, sometimes, but certainly on a yearly basis. Their needs change, the amount of food they need changes, the way they want to run their life changes, and diabetes has to fit in with that. I do say to the children "you can't ignore your diabetes, because it will come up and bite you". So, we try and get them to run their lives, respecting the diabetes, and hopefully give them the tools to manage that.

- (29) An outsider might feel that what you've described is just a series of changes in fashion. How do you see it? Is it changes in fashion, or has there just been steady progress, things getting better and better?

It's certainly progress. Whether things are getting better and better, I don't know. It's very subjective, that. It's certainly progress. We've got a lot more scientific standards and things to aim for. You know, there've been big trials in the eighties and nineties - The Diabetes and Complications Trial - that showed us that, if you get good control, you get less chance of the complications. So, we know what we're aiming for. We know averages - blood sugar averages - we're aiming for: the HbA1c. We know that we... what nutrition we want. I think there's a lot more goals to aim for, and, therefore, you could say it's, sort of, with some science behind it. And in that respect, yes, it's progress. Whereas before, I think it was just sort of a shot in the dark. We hadn't really moved on very much from knowing that, you know, you restrict carbohydrate and give some insulin, and they should be okay. Now we've actually got outcomes, and we monitor things a lot more. You know, we monitor potential complication risks, and act on that, you know, with the advent of statins for lipid management. And, you know, we screen our kids for neuropathy, early signs of neuropathy, and for renal function. Things that we weren't doing at all in the early nineties; well, certainly the eighties and into the nineties, we'd just started to look at it. But now, you know, with science, we can measure microalbuminurias; instead, we were just measuring protein - when I first started - by which time your kidneys were probably fairly damaged anyway. So, everything, now, is getting much more controllable, tighter targets. Doesn't mean the children will always achieve them, but we know what we're aiming for, and they know what they're aiming for. And, in some ways, we used to say "is this a stick to beat everybody with?", because the parents react very strongly to it. And the kids go, "well, hey, you know, it's my diabetes". But I think everybody knows what they're aiming for, and in that respect it is more progress, and it is more science-based. And the companies are looking for better and better insulins that match the physiological ones, and are looking for better ways of giving it. So, in a way, yes, we are much better. It's not just fashion, it is progress. But, you can't get away from the fact

that diabetes is a problem with the metabolism of carbohydrate, so we've got to involve diabetes management and carbohydrate somewhere. And, I imagine, we always will.