

88. Joy

(1) Tell me about your background.

Well, originally I'm from the north of England; I'm a Mancunian. And I am the outcome of a successful diabetic pregnancy of the 1940s - I should add the late 1940s, after the war, because my parents were married just after the war. My father had been in the Royal Army Medical Corps, and my mother had been a personal assistant to one of the directors, I believe, of Metropolitan-Vickers in Manchester. I have a history of diabetes in the family, although I'm not a diabetic myself, and I know my maternal grandmother always considered me as something of a miracle baby. I am an only child; I think my mother stopped while she was ahead of the game, knowing the risks to mothers and babies, at that time. And she had been in hospital for three months, prior to my birth, in order to be well monitored, and she always tells the story of being allowed out six weeks before I was born to celebrate her wedding anniversary. That would have been her second wedding anniversary. However, I was born at thirty seven weeks gestation - a forceps delivery and I don't think my shoulders have ever recovered - and I was about six pounds ten ounces. And my father always recounts his embarrassment when he used to go into the special care baby unit, because I was the largest baby in there. However, finally I was allowed home. And my mother's diabetes was not very well controlled, once she got out of hospital, and I never realised this, obviously, being a baby. But years later, when I was at Sunday school and asked to take my baptism certificate in, because we were all going to look at when we were baptised, I realised that most other children had been baptised at three months old, and there was me, nine months old, when I was baptised. And when I went home and asked about that, my father said it was because, actually, my mother's diabetes was so dreadful that by the afternoon, when all the baptism ceremonies took place in Church, normally my mother was usually on the floor in a hypo. And, therefore, until her diabetes was under control, we weren't going to get me baptised, hence, although I was born in the March, I wasn't baptised until the December. This seemed rather odd to me, and I wondered why Mummy was someone who didn't quite fit the mould, in terms of other mothers. And, of course, as I got older, I realised that: no, she didn't.

(2) Before we talk about your mother's diabetes, can you tell me about the family history that preceded?

Yes, of course. As I said, I was from a family of diabetics. My mother's elder sister had diabetes, and, in fact, was already in Manchester Royal Infirmary when my mother was taken in at diagnosis. She was in there suffering from some of the complications from diabetes, and I know the doctors were concerned about telling her that her younger sister had just been diagnosed. This, of course, was the early forties, when all the family could remember when insulin wasn't available, and to be diagnosed with diabetes was basically a sudden or less sudden death. This particular aunt went on to die of complications of diabetes in the fifties. And I can remember looking at photographs of my parents' wedding,

and wondering why my aunt had very, what I called “tree trunk legs”. And, in fact, she was suffering from diabetic nephropathy. She was a rather special aunt, in as much as she was always ill; and, of course, I was still very young when she died. And I used to go round with my mother to see her. She was always lying on the sofa with her legs covered with blankets, and, in order to improve her quality of life, my uncle had bought a television, which, in the early fifties, was very rare. So, while my mother and her sister were rabbiting away, I was sitting there watching Andy Pandy and having a great time. So, to go to my aunt’s wasn’t really a threat, it was a pleasure. However, when I asked: did my aunt have a diet very similar to my mother’s? She said “no, she has a very special diet. She has a diet which is all rice, with the occasional egg”. And, of course, as I grew up and went into practice as a dietitian, I realised that she had had a Giovanetti diet, which was a very low protein diet, and Rice Diet - the Kempner Rice Diet - which was one which enabled you to have more carbohydrate, with very little salt and potassium in the diet. So, I suppose my aunt was a bit of a pioneer in treatment of chronic renal failure, before we ever had dialysis. So, there were the two sisters who had diabetes, and then my mother had two elder brothers, in between her and my (her) sister, and they went on to develop insulin-dependent diabetes in the fifties. And they were also taking insulin, but in twice-daily doses, whereas my mother’s dose was only a single dose a day. But, of course, special diets seemed to be quite normal in my household, and it was very difficult for me to understand that other households were different to mine. I can remember sweets coming off ration in the early fifties - in 1953, I think - and all my little friends saying their fathers went up and bought a sweet shop up, because, you know, they could have sweets in the household again. And, of course, in our family, nothing changed; we just carried on as normal.

(3) What kinds of insulin were the family members on?

Well, at that time, I obviously had no idea. As a child, you look at the paraphernalia of diabetes, which was quite different to what it is today. And I always remember one of my uncles, and my mother, keeping all their equipment in an old-fashioned sort of lunch box that I think you would have got from Woolworths, and that my mother’s lunch box had a yellow top and my uncle’s lunch box had a blue top. And it seemed like an Aladdin’s cave in there, of medical equipment. And my mother’s insulin, which was Globin Zinc, which was a depot insulin, came in little boxes, which I believe were orange and blue, and my uncle’s, which were some sort of soluble insulin - now, I can’t remember the strength of those insulins - and his box was maroon and green. So, of course, as a child, I was fascinated by the thought that they had different insulins. Apart from that, some of the things that they had, which were similar, were the awful glass syringes and the huge needles, and the fact that we had the ritual, every week, of the boiling of the needle. This was done in the milk pan, which seemed to be the pan with the best bottom in it, as my mother said. And just to make sure that she didn’t crack the syringe, it used to be put on a piece of pink lint, then with water, and boiled on the stove. This was all very well, until one week, I can remember coming home from school, and there was this dreadful smell in

the house, and my mother had inadvertently left the syringe boiling, and gone off to do something else. Of course, it boiled dry, and we had this awful piece of burnt lint, however the syringe remained intact, and that was all she was worried about. The other thing that they had that, of course, was the same for both of them, was the black box, which was the Clinitest kit, which lived in the bathroom next to my father's shaving equipment. And I just thought this was another accoutrement to normal daily life. Fascinated, of course, by the copper sulphate tablet that went in with the urine, and everything changed colour.

- (4) And what memories have you got of your mother's and her brothers' and sister's diets?

Well, obviously, the best memory is of my mother's diet. She had to weigh all her food, and I just took that as normal. And we didn't... there were things that we didn't have. Clearly we didn't have sweet things, but then, to a certain extent, neither did anybody else after the war, so there wasn't anything odd about that. But there were other things we didn't have, and I always remember wondering what was the advert on the back of a bus that said "Aah! Bisto". What were the Bisto kids? Because, in our house, you didn't have gravy, you didn't have thickened gravy. You had vegetable water that was coloured possibly with a bit of gravy browning, but you definitely didn't have anything that was anything resembling a sauce. So, I used to wonder why there was something different there. Weighing food: she weighed all her food, and I still have the scales that she used, tiny as they were. But we took these scales on holiday with us. She was meticulous in what she weighed, in terms of her carbohydrate portion of her diet, and her diet sheet was stuck up, for all to see, in the kitchen. I have to say, in later years, she became less compliant, but certainly, I understand retrospectively, how in the fifties, she was still very close to diagnosis - within ten to twelve years of diagnosis - and aware that she had the gift of life and the gift of insulin. That was very important. My uncle, on the other hand, didn't seem to weigh his food in quite the same way, and would guess what he was supposed to eat. But did very well, and I think, because he was on insulin twice a day, possibly had a little more leeway than my mother did. She was very often, because she had one injection a day, going a bit off song, if you like, by the afternoon, because these insulins that she was on were depot insulins, and were starting to act more vigorously through the afternoon. So, her diet sheet included what we would term "afternoon tea", because, of course, she needed some carbohydrate. However, she sometimes decided this was something she didn't need, probably about the time when I was coming home from school. So, from a very early age, my father had instructed me what to do when my mother had what he called a "reaction". This, of course, was a hypo, as we know now. And we had a large box of dextrose, which we'd got from the chemist, and I was instructed how to make up three teaspoons of dextrose in either water or milk. By the time my mother was going hypo, she was getting not only a bit difficult to feed, but also quite aggressive and stroppy, and she'd start arguing with me - this little tot of four or five - and saying she wasn't going to eat it. And my biggest fear was that she'd fall on the floor, which had happened, and

we knew, you know, was a real concern. In those days, we didn't have things like Glucagon or Hypostop, and, you know, as a child, we didn't even have a phone, at that time, so I'm not quite sure what I would have done if she'd really gone the whole hog and passed out. But I well remember being out with her, and perhaps I could tell she was going off, and I'd need to stop and find somewhere to get her some sweet foods and feed her, so that she would get better. But the biggest problem was always we were walking somewhere, and she more or less refused to stop walking, and I knew that from what my father had said, I had to make her rest.

- (5) I well remember, when I was a little older - I was probably nine - and, by this time, we had moved down south, which was, in some ways, a huge trauma for my mother, because she was now going to have to cope on her own. And I had got my ballet exam, and because I only went to a tiny ballet school in our village, one was required to go up to Lancaster Gate, I think it was, to the Royal Ballet School rooms and do the exam, which indeed we did. And it was due to take place at three o'clock in the afternoon. Well, to our disappointment, these exams were taking place later than we expected. I went in, did my piece, came out, by which time, of course, my mother was well on the way to a hypo. She always carried sweets in the bottom of her bag, and by the time I got out, she'd already eaten all of those. We then had to hoof it back to the nearest tube station, and it was clear within a hundred yards or so of the school where I'd taken the exam, she wasn't going to get there without actually collapsing. So, in a strange place, I had to ask a passer-by where the nearest sweet shop was, and hope that I could get my mother there, prop her up outside while I ran in and bought some sweets, and fed those to her, and waited until her blood glucose got a bit higher and we were able to continue our journey home. I suppose, as a child, I just took this as normal. We lived with my mother's diabetes, we had regular meals; that was normal in our house. It was only as I got older, and started to go to other people's homes both for meals and to stay, that I realised that it didn't matter whether you ate your lunch at half past twelve or half past one, there wasn't somebody going hypo at the end of the table, and really needing to eat food at a certain time.

- (6) How involved was your father in the management of your mother's diabetes?

I think, probably, he was very involved; more so than many partners, at that time. As I'd stated, he'd been in the Royal Army Medical Corps, and so he was very proficient at giving and taking blood, but certainly giving injections. And retrospectively, I think, possibly my mother was a bit needle-phobic - who wouldn't have been with the kind of needles that were available at that time? And he would give her her injection, if he was at home, which certainly, in the early fifties, he was. She didn't want to use her arms because she felt she may have, you know, detrimental effects from that, and she wanted to wear sleeveless dresses, and so on. She wasn't terribly pleased about giving them in her thighs

for the same reason. I don't think anybody had suggested to her that you gave them in the abdomen, but the other obvious area was, of course, the bottom, which she found a bit difficult to reach, and that seemed to be a jolly good excuse for asking my father to do it. As she was only on one injection a day, this was perfectly acceptable, so he would give her her injection before he went off to work in the morning. He was also very compliant, really, regarding her diet. I work in the area of nutrition, now, as a dietitian, and I know that many people have difficulties with their partners accepting what kind of diet they may be on. But my father was very easygoing, and wasn't particularly concerned that we didn't have lots of sweet food in the house. He would just take what there was. He didn't ask for cakes all the time, although, surprisingly, his mother was trained as a *pâtisserieuse*, and I can't think of anywhere nicer to go for afternoon tea. But my father was very good about that, and he didn't expect anything extra. He was also very good at, obviously, treating hypos and thinking ahead, and thinking, if we were going out for a days out, have we got some extra food for Mummy, in case there isn't a café or somewhere nearby where we could get food for her? So, in many ways, he was very good with her, regarding her diet.

And what memories do you have of your mother's medical care?

Well, originally she was diagnosed at Manchester Royal Infirmary, but, by the early fifties, she was transferred to the local hospital - what we would now call a district general hospital. And I have one memory of going with her to her hospital visit - I think, possibly, because my grandmother had said she couldn't look after me for that afternoon. And all I remember is my mother sitting in a, it seemed, inexorable line of chairs, and this awful smell, which was, of course, the urine being boiled up and tested for glucose. And I can remember going into such a strop, when I got home to my granny's, that I vowed never to go again. When we moved south, I think my mother had also vowed never to go to a hospital clinic again! And her GP seemed quite comfortable with this, and would quite happily give her prescriptions for her insulin, needles, whatever, and, it seemed, huge cartons of cotton wool, and... which we still had, even when she died. They were like pound boxes of cotton wool, which she never ever was going to get through. But I do feel, thinking back, that because she stopped being seen by a consultant team, that, in fact, her diabetes and its complications progressed, because they went unchecked by a village GP, who really didn't have a lot of competence in the care that diabetics needed as a whole.

(7) So, talk about how your mother's diabetes progressed.

Well, finally, on one of her trips to the GP in our village, she had commented that she felt very tired all the time, didn't feel too well. And he took a blood test and found her to be B12 deficient, and she had developed pernicious anaemia. So, because of that - another autoimmune complication, of course - she was referred to the local hospital, and thereafter she had consultant input. But I think, by that time, her diabetes and its complications had progressed. When my parents moved from Surrey, and went up to live in Norfolk for a period of time, she continued to see a consultant there, and she was regularly monitored. By this

time, she'd had diabetes for thirty years plus, and she was starting to show the beginnings of complications, like raised blood pressure and some nephropathy; some kidney damage. And she was monitored quite closely, thereon in, from when they moved from their home there into South Wales, and then eventually back to Surrey, where she lived until she died. I think I first became aware of the fact that she had measurable complications when she was taken ill, when they were living in Wales, and she would have been in her late fifties, early sixties, and she had a mini-stroke and was also clearly had kidney damage. I'm sure she, herself, was concerned by this, knowing that her eldest sister had died of the renal complications of diabetes, so I think she took a little bit more care about her diet, although, through the early sixties and seventies, I think she'd been on a bit of a free-for-all. Once she had been taken under the wing of a consultant, of course, she was told that the once daily injection that she had been on was not really appropriate for good control, and, much against her will, finished up going on to two injections a day. But she had played the field a bit, in terms of diet. It didn't matter that, in the meantime, I had qualified as a dietitian, and she was never ever going to listen to anything I said; that was perfectly clear. So, she would sometimes engineer a possible hypo, eating something very appropriate at lunch-time, knowing that she could go and hide in the kitchen during the afternoon, and have the evil jam tart that she really craved. There were occasions, even though she was supposed to be more good about her diet, when she did go off the plot a bit. And I well remember, by the time my parents celebrated their fortieth wedding anniversary, which was in 1987, as a treat, she and my father went on Concorde. At this time, she was not only under the care of a diabetologist, but also a nephrologist - a renal physician - and she had told him that they were going on Concorde. And when she went to her next appointment, having been, he said to her "well, what did you have to eat when you were on Concorde? I understand it's very plush food". And she said "I ate everything they put in front of me", and for somebody who was supposed to be on a potassium, sodium and protein restricted diet, that was fair going, but why not? Unfortunately, that was one of the last treats she had, because she died a year later of the complications of diabetes, in heart failure, but she'd beaten the system, to a certain extent.

(8) Before we go on to your own career, are there any other memories of your mother?

Well, the only thing I think I've forgotten to say is, as a child, I can remember my mother, at the age of thirty six, having to have a dental clearance, and this was associated with the diabetes, obviously. And I was sent off to the shops, for a whole week, getting cans and cans of Heinz soup, which she had to live on. I can remember she had the top clearance one week, and then went back a week later for the bottom clearance. And, of course, she had to wait several weeks until her gums had hardened, and then she was able to have her false teeth made and fitted. So, I seemed forever to be taking what we used to call a bucket bag, at that time, and going and collecting cans of soup from the local grocer. I can also remember, I have to confess, deciding that I was going to swing this bucket

bag over my head on the way home, as you did. And one day it didn't quite go to plan, and seven cans of soup fell out and got somewhat dented, at which point my mother, even with no teeth, gave me what-for when I got home, because she couldn't open them very easily.

And what effect do you feel that your mother's diabetes had on your whole family life?

Personally, I don't think it has had an effect on me. I certainly think, in the early fifties, children didn't perhaps go out to tea with their friends and sleepovers, in the way that children... my children did, or children do now, so, in fact, the family unit was very much enclosed. And even the extended family unit, in our case, included people with diabetes and dietary problems. So, a diet was nothing odd to me; it was just: that's the way things are. And, in fact, I, myself, was on something of a special diet, when I was a child, so it was perfectly normal to have different things going on in the family. I think the interest for me came later on, as I was growing up, when I became fascinated by this interaction of food and my mother's wellbeing, or otherwise, and the fact that that didn't affect my father and didn't really affect me. And I'm sure, in some ways, that influenced the kind of career I went on to follow.

(9) Tell me about the path that led you to becoming a dietitian.

Well, when we originally lived in Manchester, I went to a state school, and, as a baby boomer, I was in a class of about fifty two, I think - although, for me, I was in the top three, and I loved it; I loved success, I have to say. When we moved south, in the mid fifties, my father decided that there was no way my education was going to continue in a class of fifty three, and then I went into private education in a little private school, which prided itself on just having become co-educational. I can remember most of the girls in the class were the brainy ones, and the boys were the lazy ones, so, in fact, I still had an opportunity to shine, because there were all these little boys who were never doing their work, and I was definitely somebody who wanted to succeed. I passed the Eleven Plus, and won a scholarship to a girls' public day school, although my father had already said, if I hadn't won a scholarship, he would have put me in for the school's entrance exam, and hopefully I would have passed that and gone there anyway. So, I had rather a traditional path through the private system, in terms of doing academic subjects, rather than the domestic science needlework. In fact, I couldn't have boiled an egg unless I had been trained at home, with the help of my mother and my paternal grandmother, who had obviously an interest in food, being a patisseuse. By the time I went to college and had done my A Levels, I'd also been the school hockey captain, so again, that was the trying to succeed coming out. And I did a lot of sport and exercise, and went to college in London, studied dietetics.

(10) At that time, dietetics was not an all-graduate profession. In fact, the only college that turned into a university, which was Battersea College - which became Surrey University - this was the only degree course that one

could do, and it was very science orientated. And this was definitely... although dietetics is a science orientated profession, I saw myself as not just a scientist, but a communicator. And there was no way I wanted to finish up as a researcher in a little ivory tower. I wanted to teach people, and so I went for a course, which was still, at that time, a diploma course, in order to get some practical skills. I was very fortunate, because I went to a college - Ealing College, which is now, I think, Thames University, as many of the colleges turned into universities later - and there were very few of us in our year: eight to be precise. And we were very fortunate in being able to go and visit all the London teaching hospitals. We were on a tube line, we could go up in a matter of minutes and visit a dietetic department at St George's or Barts or the Royal Free or the London, which I ultimately was... ultimately was the place where I did my practical experience. And, of course, we got a super taster of all the different departments in the teaching hospitals. At that time, in the sixties, many people who were in charge of those departments were, what I would call, dedicated unmarried women, dedicated to their profession. These were often ladies who, again, were probably from the middle classes, who had... whose parents had paid for them to go to university, possibly to do a nutrition degree, and then they had gone on and done postgraduate qualifications in dietetics. Dietetics, itself, was a modern profession. The British Dietetic Association was only formed in 1936, so, even in the mid sixties, it wasn't very old.

(11) Tell me about your training.

Well, during the sixties, of course, there was much more interest placed in diet, and its role in health. Diabetes was always going to be a big part of that training, because diabetic diets were very important. But equally, we forget, I think, today, how much drugs play a part; not only in diabetes, but in the treatment of other diseases and conditions. For example, at that time, we learned about gastric diets for people with ulcers, and there were seven gastric diets, I can remember. We didn't have diuretics in the same numbers, or ways in which we could treat people with high sodiums, so, of course, we even had low sodium milk. There was a huge influx of knowledge about paediatric dietetics, and also, of course, dialysers were advanced in the sixties, and we had renal dietetics was one of the newer things. And certainly, at that time, if you wanted to specialise when you were qualified, the 'in thing' was to do renal dietetics or paediatrics. But, I suppose, because of my background, diabetes was the thing that I wanted to study more. The training was slightly different, in those years, because, although we did four years' training - which was a long training period, at that time - we did three years of theory, and then, in the fourth year, we went out and did our practical experience, and then came back and did what we called part two finals after that. I trained through the sixties, but did my part two finals in 1971, and was very proud to get my Council for Professions Supplementary number, which was D - which stood for dietetics - 1281. So, at that time, there were only just over twelve hundred of us with a number, and probably only about eleven hundred of us practising; nearly all of those, at that time, in the NHS.



(12) What were you taught about diabetes?

The most important thing I remember about diabetes in the sixties, when I was taught, was that you were either insulin-dependent or you weren't. And if you were insulin-dependent, you were definitely diagnosed before the age of forty, and if you weren't insulin-dependent, you were diagnosed after the age of forty. Clearly, as my mother had been diagnosed in her twenties, that seemed to fit the bill. But I always thought it was rather amusing that, if you got to forty one, how did we decide that you were non insulin-dependent rather than insulin-dependent? I think what was also interesting, at the time, was that we never ever thought of non insulin-dependent diabetics needing insulin. And I think that was a reflection of the fact that non insulin-dependent diabetics often, of course, had died of the complications of diabetes before they ever got to being insulin-requiring. We didn't really understand that what we call now Type 2 diabetes was, in fact, a wolf in sheep's clothing, and that people who had developed non insulin-dependent diabetes had probably had diabetic symptoms masked for about eleven or twelve years, and that they already were presenting with some of the microvascular complications that we now know are very often apparent. And I think we were classing diabetes in a very black and white way, at those times. And also, during the war, I don't think we had many obese people, thanks to the likes of McCance and Widdowson, who were nutritionists in the thirties. The war had come, and the work they had done had shown what people needed to eat, in terms of what their requirements were, and, therefore, people tended not to be obese. So, this whole idea of Type 2 diabetes and insulin resistance was much less prevalent than it is today. And, therefore, we didn't understand that that was another aspect to the disease. More recently, of course, we know that that is the case, and that - because of, again, the advancement in drugs, and attacking, shall we say, hypertension and those aspects of heart disease that we do so now - that those with non insulin-dependent diabetes finish up requiring insulin. They are still Type 2 diabetics, but they become insulin-requiring. When I was training in the sixties, and practising in the early seventies, you never ever saw a non insulin-dependent diabetic using insulin.

(13) What did you do after you graduated?

Well, initially I took a post in South Essex, and used to work with the diabetic consultant there, and we used to go to the different hospitals doing diabetes clinics. At that time, as I said, there weren't that many dietitians in the country, as a whole, and what many consultants had had to rely on, until that time, were diets that they had bought from what was then the British Diabetic Association, which they kept in a drawer in the consulting room. And newly diagnosed diabetics, if they were not fortunate enough to have a dietitian on hand, were just given a diet sheet that had been purloined from the BDA, and told to get on with it, basically. So, dietitians were seen very much - certainly outside the teaching hospital environment - as icing on the cake, if that isn't the wrong expression to use. And I used to do the diabetic clinics with this particular consultant, and I would sit with him until there was, perhaps, a newly diagnosed

patient had come to see him. And then I would take this patient off to my own consulting room, and assess their diet, and tell them how they may need to make some changes in order to get by and improve their blood glucose control. Of course, at this time, we have to remember that we still didn't have blood glucose monitoring for patients, and they were relying on their urine testing. And so, of course, it was still very hit and miss as to whether they had good control or bad control, and we just had to play it by ear. And weight became quite important in deciding as to whether they were good or bad. If your weight had gone up, then probably you were misbehaving, but somehow managing to avoid glycosuria. And if their diabetes wasn't very good anyway, of course, they may have lost weight, because they were leaking carbohydrate through their urine.

(14) And what did you do after your Essex job - and give dates, if possible?

Well, then my husband's work moved to Surrey, and I can remember going to the British Dietetic Association headquarters, which, at the time, were near the Brompton Oratory, in a very tiny office run by a lady who chain-smoked. And I walked into the office, and looked at her through this fog, and said "can you tell me the likelihood of getting a job in Guildford, because that's where we're going to live when we move to Surrey?" And she had said "oh, you'll never get a job there. There are three people already sharing, I think, 1.5 whole time equivalent dietetics, and they cover for each other", and that was that. So, we moved over to Surrey, and I decided to do something completely different, and used my skills in the personnel section of a government department, recruiting, as it happens, engineers. And had great fun with all these men, telling them off for what they should and shouldn't do; so, in some ways, it was quite like dietetics, because I was ruling the roost in terms of what the rules were. I then took time out of work to have my two children, although keeping in touch with my GP's surgery, who were thrilled to know they had a dietitian on the books as a mum. And I occasionally used to do talks for them; to mums and babies, and, occasionally, diabetics who came into the surgery. Then I went back into practice, when my children had started school and nursery school, and was able to get a job at my local district general hospital, initially working part-time, but, again, having some input to diabetes, which was my specialty. And it was interesting how things had changed, even in the five or six years I had been out.

What years were these?

This was from 1974 to 1979. And I went back into practice as the new hospital was opened in January 1980. And, I have to say, I've been there ever since, working my way through all the different changes that have happened in the NHS through that time, and also all the different changes that have happened to diabetes care in that time.

(15) So, what are your memories of diabetes care from 1979?

Well, certainly things were becoming much more structured, and in 1983, the British Diabetic Association published dietary guidelines for diabetes for the eighties. And this was quite interesting, because we had been taught at college

about carbohydrate exchanges - ten gram exchanges - and the new idea of the eighties was that diet and carbohydrate should not necessarily be quantitative, but qualitative. And a lot of research that had been done in America, up to this time, had shown that as long as carbohydrate was of a high fibre, slowly digested form, that it would not affect blood glucose very much, and that the emphasis on exchanges was possibly inappropriate, although patients should still avoid sugars and sugary foods. I have to say, I didn't necessarily concur with this, but that may have been my own personal view, having watched my mother and some of her family cheat, shall we say - or not cheat - on the number of slices of bread or potatoes they took with the meal. Certainly, as far as I was concerned, there was an effect, not only in quality but quantity of carbohydrate taken. However, one is required to play it by the new rules, and those were rules which we then followed. And for many diabetics diagnosed through the eighties, certainly those which were not insulin-dependent, these new rules seemed to hold good. As long as you told someone to eat wholemeal rice not white rice, and wholemeal bread rather than white bread, then their blood glucose measurements seemed to be quite acceptable. By this time, glucose meters were on the scene, although they were very expensive. Just harking back to my mother, I can remember she had one of the early blood glucose meters, and I think it had cost about eighty pounds, which, for many people, was completely out of their reach. And certainly, even if they could have afforded that one-off cost, they couldn't have afforded the strips that went in them, because, again, at this time, they were not available on prescription. So, diet was still a key, and urine testing for most, and at least we thought we had an easier way to go with diet. Subsequently, in the early nineties, the BDA put out another policy statement, whereby sugars, to a certain extent, were allowed in the diet, up to twenty five grams a day. And I can remember many a conversation I had with diabetics, who said "does that mean I can have a teaspoon of sugar in every cup of tea I have for the day?" And I said "no, not necessarily". But at least it meant that some of the old school ideas about: you are not allowed thickened sauces, and you cannot have tomato ketchup, went by the board. And we tended to encourage people that if you wanted a bit of tomato ketchup on your chips, for goodness sake, that was okay. My concern was, probably: should they be having chips at all, because maybe they were obese Type 2s, and seeing me as a way to get to the chip shop, because "the dietitian says it's all right now" was another trauma that we had to live through.

- (16) However, I think, as I've said before, a lot of the difficulties, for me, were around the fact that you still had to consider the amount of food that you had, as well as what kind of food it was. And people who were eating chips, I thought, they're never ever going to be having seven or eight chips, they're going to be having an enormous plateful. I'd never really given up on ten gram exchanges, and I think, as the eighties went on, it became apparent that for some patients, measuring the amount of food, even if it wasn't on scales, became quite important. Diabetes, after all, has always been a condition with a lot of paraphernalia attached to it, and, as the

eighties continued, the boring old urine testing only bits were overtaken by the development of blood glucose monitoring meters. But also, with all these developments, the poor consultant, who'd only ever had to put his hand in a drawer to get out a diet sheet, found himself rather overrun with things to do. And while he appreciated the efforts of a dietitian in taking the diet problem away from him, there were other things that diabetes now meant; they needed... people with diabetes needed to know about. And certainly, in the eighties, in my hospital in Guildford, we acquired our first diabetes specialist nurse, and here were the beginnings of a proper multidisciplinary team. And our diabetes specialist nurse also was a bit special, because her husband's sister was an insulin-dependent diabetic. So, we both brought to the table our own family backgrounds and knowledge, that perhaps meant we had more of an idea of what patients had to cope with when they were diagnosed. But she was - and still is, because she also, like me, has been there a long time now - was there to teach patients both urine testing, blood glucose monitoring. And certainly, we were both sufficiently experienced to know that it wasn't only just carbohydrate type, but carbohydrate load that mattered, and we had never really abandoned ten gram carbohydrate portions. And for patients who were very interested, we still taught them how to assess their carbohydrate - not necessarily by weighing on scales, as I've said, but by household measures - so they got some indication of control, and what those amounts of carbohydrate did to their blood glucose in response to the amount of insulin they took. And I think that was primarily because the... with the investigation, using blood glucose monitors, they had much more accurate idea of what was going on.

(17) Can you tell me more about your multidisciplinary team, in the 1980s?

Well, as I say, we started with our diabetes specialist nurse. We already had a chiropodist - now called a podiatrist - who worked with us, and a consultant, and... two consultants, in fact, and their registrars, and we started to come together as a group. And in our particular area, we extended our multidisciplinary team, in a way, to include GPs, and the clinics that they ran became also multidisciplinary. At the end of the eighties, of course, the NHS was going through huge reorganisation, and this was the era of fund-holding and non fund-holding GP practices. Being Surrey, we had rather a lot of fund-holding practices, and it was there where they took on a lot of the care of diabetics, certainly Type 2 diabetics, who were non insulin-requiring. By this time, I was a District Head of Service in dietetics, obviously with an interest in diabetes. Many of these GP fund holders wanted to extend their care, not only of themselves to diabetes, but to form their own mini diabetes clinics, and I literally sold them dietetic services to put together their own MDTs. And they would have mini diabetic clinics, with a podiatrist also in attendance, possibly an optician, and their practice nurses were trained by our own diabetes specialist nurse. We also ran what we called "share care" meetings, which still go on now, where the GPs and the practice nurses would come to meetings with the secondary care MDT, which is

myself and the specialist nurses and the consultants, and we would swap stories, but also give papers on new advances: what we thought was the right treatment for hypertension, say, or when they should refer people with diabetes with renal complications, et cetera, et cetera. And those who were having particular diet problems would perhaps be referred into the hospital for review. So, it's been a huge leap, in the last fifteen years or so, in terms of ongoing care for diabetes and dietetics, because we're providing those services over a much wider area, and I think it's important that we do so. I think we have lost something, in a way, although we've gained something. No longer are dietitians seen as the nasty people - you get sent to the dietitian if you've misbehaved - but we're also seen as a resource, now, for patients when they've not necessarily misbehaved, but we can give them advice about, you know, what's the best margarine to use; is there any point in using one of these specialist margarines if they're on cholesterol lowering tablets, and so on. And I think there's a much healthier interaction between those professionals and patients, and I would like to think that that has improved the service that patients get.

(18) Can you compare hospital care and GP care, in the 1990s?

Well, I have to say, in the nineties, although these fund-holding GPs were very keen to look after their own diabetics, there was a certain reticence about looking after people with diabetes who required insulin. I don't know whether GPs were frightened of needles, or they thought that patients would be, but they felt more comfortable looking after Type 2 diabetics. And, of course, if we remember 75% of Type 2 diabetics are obese, then, to a certain extent, their care was surrounded by needing a patient to lose weight in order to improve their diabetic symptoms. So, if you look at the differentials in care between GPs and hospital services, it was probably that, at that time in the hospital, we saw fewer and fewer non insulin-requiring diabetics. And what we found ourselves seeing were not only just insulin-requiring diabetics, but insulin-requiring diabetics who had problems. And so, in effect, the hospital service became much more specialised. We also, of course, at that time, saw more Type 2 diabetics who had become insulin-requiring, and they, in many instances, had their own problems, because going onto insulin, for Type 2 diabetics, not only was trauma for them, but often meant that they gained an awful lot of weight. Insulin is, after all, an anabolic hormone; in a way, sim... not similar to a steroid, but is one in which it is involved in metabolism in the use of all food, not just carbohydrate. And many of these Type 2 diabetics, who went onto insulin, put on an enormous amount of weight, at which point they were presented to the hospital clinic, very distraught, "go and see the dietitian, you've put on a lot of weight". And they're saying "what can I do?" This in itself meant that hospital dietetics also looked at other ways in which we could treat these probably very insulin-resistant cases. And there were instances where research was done looking at very low calorie diets for these patients, and seeing if they would pull their weight down sufficiently to enable them to cut back on their insulin dose, certainly, and, in some instances, come off insulin altogether and go back onto oral medication. That was seen to be a somewhat bizarre or odd diet for diabetics. Very low calorie diets had been

the norm, in the eighties, for people who basically just wanted to lose weight, with this pyramid selling of certain commercial, very low calorie diets. And, of course, they'd gone into disrepute, because those original diets were very, very low calorie, and there had been deaths reported in America, because people had literally lost heart muscle and died.

- (19) However, other amusing things that came through, from odd treatments, were things like low glycaemic index specialist foods. And I can remember the university, close to our hospital, developing what they called Guar crackers, which were very low glycaemic index crackers, which they were hoping that their diabetic patients would eat. Unfortunately, while those diabetics were not being seen in a clinic at the university, they were pitching up at our clinics, which was all very well and good, but I can remember one day, a lady coming and saying "I've got a present for you". And I thought "gosh, this is nice", you know, "somebody's very pleased with what we've done for them". And she put on the desk these awfully hard crackers, and she said "if you think you can eat them, then go ahead. I'm not eating them. I don't care how much they're supposedly going to help my diabetes and my blood glucose, there is no way I'm eating those", which was another way of underlining the fact that we need to work with our patients, not necessarily just in the interests of science. And I think that is one of the things that has developed during the last ten or fifteen years, that, while we see ourselves as MDTs - multidisciplinary teams - we have to make sure that the patient is part of that multidisciplinary team, and we're there to help them. And developments like the Expert Patient Programme underline that fact, and also things like DAFNE, which is Dose Adjustment For Normal Eating, and other specialist group teaching sessions are showing that patients need to be their own experts.
- (20) The diabetes specialist nurse, with whom I work, has been involved in the Expert Patient Programme, and both she and I now are just learning how to be DAFNE educators. And recently, we went to our first week of training, as onlookers, at another training session for patients, where the patients go for their week of tuition. It was invaluable for us to see these patients come together. And on the first day, they were very, I think, possibly, angry about their diabetes, anti the training, unsure about what they were going to get out of it. But after a week of teaching with a dietitian, a diabetes specialist nurse and with consultant input, they felt much more assured about what they could achieve, and how they could improve their control. And it was really good to see their input with each other. I also felt that one of them, in particular - who I chose as a case study, as it happens - felt very alone with her diabetes, and this had been an opportunity for her to see that she wasn't alone, and that, in fact, there were others like her. And I suppose, in some ways, I felt my mother was fortunate that, in fact, she was never alone with her diabetes, because she had a whole family of diabetics around her. So, it wasn't odd for her to have insulin-dependent diabetes, unlike this young girl, who lived alone

and felt very isolated by it.

Do you feel that the value of the DAFNE course is actually what is taught, or simply the mere fact of all meeting together and getting some concentrated attention from health professionals?

I think it's a mixture of both. I think if you look at some of the research that's gone on, over the years, like the Diabetes Control and Complications Trial, and other research, that if you give people attention, they do better. They like attention, and it's also as if they're the chosen ones. I think what was nice in this course was that they did gain a lot of respect for each other, and they understood other people's problems, which weren't necessarily the same as their problems with diabetes, but they could see how that for some people in different social circumstances, there were different problems for them. There were people who had come from a good background, but actually had a huge issue with diabetes, perhaps felt irritated by it, and others for whom they were just going to go with the flow and get on with it, but they didn't have access to shed loads of fruit, because they didn't have the money to buy it. And I think it was an understanding of each other that helped them to gain strength. And certainly they, as part of the DAFNE programme, meet again to see how they're getting on. And we have asked - I think we were the first observer group to ask - if we were allowed to go to that meeting, a couple of months on, because we too got so involved with the group that we wanted to know that they were getting something out of it, because we, as potential educators, would like to think that those people, who we invested so much time in, would also not only get something from it, but be able to carry that forward. I think the message that DAFNE gives to people is that knowledge is power, and that a lot of those people came to the course with insufficient knowledge, for whatever reason. I think the diagnosis of diabetes is traumatic for many people, and they can't take on board all the things they need to know, and I think that is very difficult. I can remember seeing some research that said: if you have a consultation with somebody, they take note of what you're saying for 10% of the time. Given that very often, with newly diagnosed patients, diet is, after all, the corner-stone of treatment, and we would spend an hour with a patient talking them through what they do, the changes they need to make, you sometimes get to the end of a consultation and think "hmm, I wonder which ten minutes they took in, and could I have not bothered speaking for other fifty?"

- (21) I think that perhaps holds good, quite a lot, for another area of diabetes which I work in, which is gestational diabetes. This seems to be more and more prevalent, or maybe it's just the area within which I work, where, of course, there are many more mothers who are older when they start having their families, so, if you like, they are already on the path to insulin resistance. They may also be slightly overweight - I wouldn't dare say obese - and that as their pregnancy progresses, they are more likely to develop gestational diabetes. Having children of my own, I can't think of a worse time to be diagnosed with yet another problem, when you're

coping with pregnancy. And a lot of these women are quite emotional when they're told that they have diabetes, and it's a question of working with them, and trying to assess their diet, and enable them to get excellent blood glucose control, because we're much more tight on blood glucose control for pregnant women than we are even with non pregnant diabetics. And they've always got that fear of needing insulin, at the back of their mind, and they really, really don't want it. This was a... something that they got into that they never ever wanted to happen. And also, what damage has the diabetes done to their baby? And I think that's a very real fear, because, even with all the advances in obstetrics and in the care of diabetes, there are still deaths. And we have had deaths in our clinic, and sometimes you can explain them and other times you can't. And that's very traumatic for the mums, and the dads.

- (22) You've mentioned obesity quite a few times. Can you talk about being a dietitian, and trying to persuade patients to do what you want them to do?

Well, obviously, it's very difficult. I can remember one of my son's friends once gave me a mug. It was a Garfield mug, and it said "diet is 'Die' with a 'T' ". And I wasn't amused, at the time, but I suppose, really, it is quite funny. And I also alluded to this when saying, you know, "you get to see the dietitian when you've misbehaved". We want to be a resource rather than a threat. It is very difficult to get people to lose weight. You will have seen on the news, oh, weekly, almost: we are in an obesogenic society. I think for every person in this country, there are three thousand eight hundred calories available to them to eat. Of course, the fact that they only need fifteen hundred to two thousand is completely by the bye. When you go into the supermarket, and there are thirty odd thousand lines to choose from, it's very easy to make the wrong mistake, especially if they have a bakery section and all you can smell are hot muffins or doughnuts, or whatever. I think, in dietetics, we've become much more aware of the reasons why people become obese, and it's a lot more to do with the psychology of what makes people eat, and why do they not have the willpower to succeed. And, in some ways, I think our profession have become much more clinical psychologists than dietitians. I know some young dietitians will say to me "well, actually, I knew what I wanted to achieve, diet-wise, with this particular patient, but I spent most of the interview trying to ascertain why he really couldn't resist four doughnuts as an afternoon snack, rather than telling him he should be taking two pieces of fruit". And I think we have got more and more to realise that we have to look at what people can achieve, rather than what they should achieve, and also marry that up with exercise, because that's the way we are going to improve the lot; not only for the obese, but for the obese diabetic. I very often say to obese diabetics "you have, in part, developed your diabetes through resistance to insulin, and if you were only able to take more exercise, you would make yourself more responsive to the insulin, which you do produce, which would improve your diabetic control". But it is difficult. Some people live to eat, and others eat to live. And sadly, I think we are reaching a society where



people live to eat, because there's so much choice on the menu, so to speak. I think it is difficult for people to maintain dietary control, and I think, even with the help of drugs, it is difficult, even with the help of what we call bariatric surgery, where there is intervention for people who are obese. Somehow, if you really want that Mars bar, you'll find a way to liquidise it and take it, and exceed in the number of... the small number of calories you are allowed, even if you've had gastric banding, although that is something that morbidly obese people with an additional condition, such as diabetes, are now allowed to pursue.

(23) Looking back on your memories of your mother's diabetes, would you like to compare her life with the lives of your patients now, in 2007?

Well, I think life for patients in 2007, I have to say, is better than when my mother was diagnosed. Certainly pre-NHS, most people with insulin-dependent diabetes had to consider the cost of insulin. Certainly my father factored that in when he considered what he was going to do, if he did indeed ask my mother and marry her, because that was going on pre-NHS, and he had to know he could afford to buy any insulin she needed, or any other equipment, for that matter. Clearly the NHS has been a boon to the cost of diabetes to the individual, although, of course, we all pay in our taxes. In operating in an area where I do - looking after diabetics who are pregnant, or gestational diabetics, people who develop diabetes during pregnancy - of course, there is very little comparison. There was my mother staying in hospital for three months, and these people, these days, yes, they come to clinic very frequently, maybe every other week, and see the multidisciplinary team, but they're not required to stay in hospital in the way she was. And all in all, although, as I say, there are a few deaths, they are very, very few compared to the forties, when I was born. So, I think the outlook for diabetes, now, is much better, and in terms of diet, there is much more flexibility. I think that has come about because, along with flexibility of diet had to be flexibility of insulin and insulin devices. And when you think of those old glass syringes with the needle that you carried on using till it was blunt, and the insulin pens and the blood glucose monitoring that we can do now, there is just no comparison. And people with diabetes now have every opportunity to be very fit and active, and lead long and healthy lives.