#### 93. Pam Dyson

## (1) Tell me about your background.

Well, I'm one of four children. My father was in the Air Force, he was an officer in the Air Force, and he and my mother married quite young, and managed to have four of us in four and a half years. I can't even think how she coped in the beginning, but that's it. And we travelled a lot when I was very young, and, as was common at the time, by the time we all reached the age of eleven, we were all sent to private boarding schools. I think the Royal Air Force actually helped to fund that. So, I went to a boarding school in Bournemouth, a private girls' boarding school. And I think I must have been thirteen or fourteen when I happened to read an article in The Times about dietitians, and decided that's what I wanted to do. So, I'm one of these people who knew very early on what it was they wanted to do, and, from then on, my O Level and my A Level choices were all about what I wanted to do and where I wanted to be. And I think I'm a natural scientist, anyway, so that wasn't an issue. So, I left school after A Levels, and went straight up to Leeds to study to be a dietitian.

What kind of people were studying with you?

This was in 1973, when I went to university. It was a female-dominated profession; in fact, I think it was five or six years on before the first male arrived to study dietetics. And everybody came from a similar background to myself; I would say strictly white, middle class, well-educated girls, with a strong interest in food and telling people what to do.

### What was the degree called?

It was actually the first intake of a new degree course, and it was called a degree in Human Nutrition and Dietetics. It was a four year course. We spent the first two years at university, then we spent a year out working, which included nine months in a hospital as a student dietitian, and then we went back for our final year.

Describe the course from year one.

Year one started with backgrounds to biochemistry, physiology, statistics, general nutritional information. There was almost no clinical work at all, in the first year; it was basic nutrition. By the second year, there was more application, so we learnt about different diseases, where diet would be important, and I think that was probably the first time the word diabetes was mentioned.

### (2) Can you remember what you knew about diabetes by then?

I remember knowing nothing about it at all. The only vague memory I have is, when I was at boarding school, one of the girls who was in the year above me was diagnosed with diabetes, and she was sent home and never seen again. Now, whether that was because her parents felt the school couldn't cope, or the school felt they couldn't cope, I don't know. But it seemed like something that was

socially unacceptable. That was the only experience I'd had of diabetes, before then.

So, tell me about your first clinical experience.

My first clinical experience was when I was a student dietitian at Addenbrooke's Hospital, and in those days, it was a trial by fire. The senior dietitian felt very strongly that young dietitians should be exposed to what happens in a hospital on their first day, to see whether they could cope or not. So, on my first morning, we had to go through a ward round on the renal ward. Now, in those days, dialysis wasn't as available as it is now, and there were two people who were actually dying of uraemia - they were in chronic renal failure - on the ward. So, they had catheters in, they were very yellow, and obviously very unwell. And it was a very difficult ward round to do, and my fellow student, who I was studying with, fainted, and that was not uncommon. And I don't know why this was done, but I think it was possibly the idea that we should toughen up, and know what we were going to be exposed to. I don't think it's the best way to expose young dietitians to what goes on in hospital, but I think I can see... I think I can understand the principle behind it, although I don't agree with it.

How old were you?

I was - this would be in 19... - I was twenty; yes, just twenty.

Describe what happened at Addenbrooke's.

Addenbrooke's was a teaching hospital, so there was a lot of research and a lot of teaching going on, and, interestingly enough, it was at the forefront of renal work, so there was a huge component of renal work. What happened, if you want a typical day, is we'd start work at eight o'clock in the morning, and every patient who was on a special diet had a different coloured sticker, according to the diet they were on. So, low-fat was yellow, the different renal diets were orange and green, I think, and diabetes was red. So, when they were given their menu cards - and they were given those twenty four hours in advance, so they had to choose their meals for the next day - they were given a card with a sticker on, and they ticked what they'd like. They were given three or four choices for a starter, a main course and a pudding. And we sat there every morning and went through their choices, and changed them if we thought they were inappropriate. And these choices were then delivered to that patient, so quite often a patient got a meal that they hadn't chosen in the first place. So, that's what we did for the first one and a half hours every day. Then, for the rest of the day, if you were covering outpatients, you'd go and sit in the outpatients' clinic and see outpatients. If you were covering inpatient work - and we did every... we were exposed to all the different things, so one week we'd be doing renal, the next week we might be doing the gastro ward - so we would spend the rest of the day on the ward or in outpatients, always supervised by a dietitian, a qualified dietitian.

(3) Were many people admitted to the wards?

I think because Addenbrooke's is a large hospital, yes, there were, and specifically for people with diabetes. Certainly in those days, all people with Type 1 diabetes were admitted as inpatients to be stabilised on insulin. We didn't do anything as outpatients with Type 1. The people with Type 2 diabetes were seen as outpatients, but in terms of diabetes, the admissions were nearly all Type 1. Of course, someone might come in with a broken leg, who happened to have diabetes, but, of course, that wasn't the reason for their admission.

Just sticking with the ward, before we go to the outpatients' clinics, can you remember what the treatment was for the Type 1s who were admitted?

When they were newly diagnosed on the ward? The first thing we did was they were taught the rudiments of how to inject, of course, using an orange, in those days, and, of course, in the seventies, we were still using the old metal syringes, and all the rest of the paraphernalia. We taught them how to sharpen their needles. This, I have to stress, wasn't done by the dietitians, it was done by the nurses. What the dietitian had to do was go and teach them about their diet, and, in those days, we had very strict prescriptive diets. The dietitian's job was to decide what the person would eat, and they then prescribed a diet. And, of course, we used the exchange system, which is a way of restricting carbohydrate.

Can you explain the exchange system?

The exchange system was not well understood by many dietitians, and certainly not understood, in my opinion, by the majority of patients. It was based on the idea of a ten gram carbohydrate exchange, so we would give people lists of food that contained ten grams of carbohydrate, for example, a small apple contains ten grams, a thin slice of bread from a small loaf contains ten grams, two cream crackers contains ten grams. So, we would give people a long list of foods, all of which contained ten grams of carbohydrate, and they counted as one exchange. We'd then say to them, for breakfast you can have, for example, three exchanges, so they would choose three items from the list. It was supposed to give people more flexibility and choice, but I think created a lot of confusion for a lot of people.

Were people thinking in grams, back in the 1970s?

I don't think people thought in grams at all, everyone thought in ounces, and that's why it was decided to call a food that contained ten grams of carbohydrate one exchange. So, you wouldn't say to people "you're having thirty grams of carbohydrate", you would say "you're having three exchanges". So, I wouldn't think most people understood that one exchange contained ten grams of carbohydrate, they just knew it as one carbohydrate exchange.

And did people mainly work on sight - you know, a small apple - or was there a great deal of weighing?

When I first started as a student, although this had disappeared by the time I was qualified, what we used to do for people with Type 1 diabetes is we gave them a little set of balances to use, and we would tell them to weigh their apples

and their bread. And another way of doing it, we tended to use exchanges, but sometimes, especially for the Type 1s, you would say, they would have four ounces of apple, or three ounces of bread. I can't imagine someone preparing a meal, and not being able to sit down and eat it until they'd weighed everything, and cut off a certain amount to make sure their foods weighed the right amount. It seems inconceivable, now, that we were expecting people to do that, but it was the way things were taught, at the time.

### (4) Were you given a specific time to talk to patients on the ward?

It was felt, at the time, that most people with diabetes would be in for about a week or so, while they got stabilised on their insulin. And the dietitian was expected to turn up, when summoned, in order to give the person necessary advice about their diet, and that was usually judged by the ward staff. I distinctly remember being called in, one day, to talk to a man, and it was half past twelve. And I walked in, and we started talking, and he obviously wasn't able to concentrate at all, and I think we both got very frustrated. I felt I was explaining things to the best of my ability, and he was quite open about the fact he had no idea what I was talking about. And it turned out that, at the time, they'd delayed his lunch in order to give him a deliberate hypo, so he'd know what the symptoms were like when he went home. And I think he did not like the experience at all, and certainly it was not a good time to be talking about food to him.

Was that standard practice, for each person to have a deliberate hypo?

For people with Type 1 diabetes, in Addenbrooke's, in the seventies, they were given deliberate hypos, so they knew what the symptoms were like. Now, interestingly enough, some people have found that very useful, and I've heard them say to me "that was so useful, because when I went home, I knew what the symptoms were, so I could recognise them". Other people have intimated me that, actually, that's an abuse; that deliberately doing that is an abuse and shouldn't be done. And I think it depends on the individual, as to how they reacted to that. It's no longer practised, I hasten to add.

Any other memories of life on the wards?

I have a distinct memory, of the time, that in Addenbrooke's, the dietitian's office was right next to the kitchen, in the bowels of the building, and that was because dietitians were also involved in food production, especially for the special diets. So, it was the job of the student dietitian, every day, to go into the kitchen and produce the puddings - the low-sugar puddings - for people with diabetes. So, we would make milk puddings with sweetener rather than sugar, we would make custard without sugar, we would make pies and sweeten the fruit with a sweetener. And so, we were involved in food production as well. It was somewhat disheartening, when you'd spent all this time producing this food, to go on the ward and see it had all been left!

Now tell me your memories of the Addenbrooke's outpatients' clinics.

The outpatients' clinics, for people with diabetes, took place on a Monday morning. They were enormous clinics. There would be six or seven doctors in clinic, each seeing ten to twelve patients. Most patients would arrive at similar times. They didn't have timed appointments, they just all turned up together, so we'd have a huge waiting room full of people waiting to see the doctor. And the doctors would just work their way through the patients, to the best of their ability. We didn't have a specific office for a dietitian, but as diet was perceived as important, the dietitian had to be in attendance, but we actually did our consultations in the waiting room, surrounded by other patients, while the patients were waiting to see the doctor. I don't think the idea of patient confidentiality occurred to anyone, at that time. So, that's what we did. And it was very difficult, for both the dietitian and the patients, to try and have some kind of frank exchange of views, with everybody else listening.

Particularly given the shame attached to overweight?

I think it was... People, typically, have a great deal of difficulty in talking about what they do, especially when they feel they're going to be judged. And when you've got an audience of a hundred, on top of that, I think it's almost impossible to do any kind of effective work.

(5) One of my strongest memories, from that time - which was very embarrassing and humiliating at the time, but which has been invaluable to mewas, as a student, I was expected to see people with Type 2 diabetes, as it was considered mild and a student could cut their teeth on them. I was always supervised by a qualified dietitian, but I was sent to see a middle aged woman, slightly overweight, to have a discussion with her about how things were going. Of course, in those days, we had no measurements of glycaemia, like A1C or blood glucose monitoring. We would just test their urine, and she had a very strong positive test - there was a lot of glucose in her urine - so we can guess her diabetes was not well controlled. And I started doing the diet history. All dietitians were trained to take a diet history; you would ask people what they'd eaten over the previous twenty four hours. The previous day, of course, had been a Sunday, and she'd had a big roast dinner for lunch. She was only supposed to have four exchanges, and she'd actually had five, so I started on the ridiculous conversation about: next time she had Yorkshire pudding, she shouldn't have custard with her apple pie, or maybe she should have one less potato. And it was talking on this system of exchanges, and I was basically telling her that really she had had five exchanges, and she should have had four, and this was how she could do it. And she was getting crosser and crosser, and eventually she turned to me and said "why you should think I should sit here and let a slip of a girl tell me what to do". And I was completely dumbfounded by this, on loads of counts, but firstly because she was daring to challenge me. I was the expert here, I knew what I was talking about, she didn't, and she had no right to say that to me. But actually, more than half of me thought she's absolutely right. What right do I have to

sit here and tell her what to eat? She didn't choose diabetes. This is something that's happened to her, without her consent, and here's some know-all telling her what she should be doing about her Sunday lunch. I think it was compounded by the fact that two minutes later, of course, my supervising dietitian bustled along said "now, just be nice to her, she's only a student. And anyway, if you don't do what we say, you're legs will drop off or you'll go blind". Now, I'm sure she didn't actually say that, but she did intimate that it was really important to stick to your diet, because otherwise you would suffer the complications of diabetes. And, of course, this just made this woman crosser. And I have to say, on reflection, I'm so glad that happened, although I was so embarrassed, because, of course, everybody else was listening, and more than half of them felt sorry for me, but they also felt the woman had a good point.

Now, you can't remember whether your supervisor exactly threatened loss of legs or sight, but do you think such threats were used by dietitians, at that time?

I know for sure, because I've heard that since, and this was in the eighties, when I was working in Bath. And I've actually heard a dietitian say it, so I know people did say that. And, in fact, we were trained by a very interesting woman at Leeds, who used to give us useful phrases. For example, when we met someone who was overweight, who was struggling to lose weight, and would say things like, you know, "no matter what I do, I can't lose weight", she recommended we come back with the reply "no fat people came out of Belsen". I have never used that phrase, and I never would, but that was something people thought about, in those days. But in order to get your point across, it didn't much matter what you said.

(6) Then you went back from your Addenbrooke's placement to continue with your Leeds degree. And at the end of that degree, how much would you say you'd learnt about diabetes?

I think most students, at that time, felt they'd learnt far more from their student placement than they did during the theoretical stuff they did at university. I think we probably spent a fortnight on diabetes, in whole, while I was at Leeds, and in the last year, we spent a week on it. And typically, we would take a disease for a week: we'd look at most aspects of it, we'd spend a day in the kitchen doing diet cooking, when we'd have to produce a day's meals for someone with diabetes. So, probably about a fortnight, but no more than certainly we spent on renal disease or any of the gastro diseases.

And then, what was your first job, after you got your degree, in 1977?

When I left Leeds, I think it was pretty clear that I didn't want to be an inpatient dietitian. I don't think I had the capabilities or what it takes to work on a ward. And I've always been interested in research, and I was lucky enough to land a job at the Dunn Nutrition Unit in Cambridge. I was working for the Medical Research Council as a junior nutritionist, and we were working on a family food survey that was sponsored by what was then MAFF, and is now DEFRA. And

basically, we just took a random sample of people in Cambridge, knocked on their doors, and asked if a family would complete a food survey for a week, and, of course, there were some people with diabetes included in this survey. I think what struck me then was the difference between what people with diabetes were eating, and what the rest of the family were eating. I particularly remember one child, who'd been invited to a birthday party during the week that they were filling in everything they were eating. And instead of going to the party and eating the food that was provided, because they'd been given such a strict diet, this child's mother actually packed her up her own tea, and she had to take this. So, while the rest of them were enjoying sausage rolls and birthday cake, she was eating this special meal that her mother had prepared for her. It was further compounded, about this time, that I started to have some personal experience of diabetes, because my step grandfather, who was then in his mid sixties, was diagnosed with Type 2 diabetes. And, of course, he was very worried and concerned by the diagnosis, and assumed I was the expert and asked me a lot of questions. He was widowed, at the time - my grandmother had already died - and he was receiving Meals on Wheels; he got special diabetic meals from Meals on Wheels. But as treats, I used to make him special cakes: fruit cakes made with Sorbitol instead of sugar, and I'd often take him round a pudding or a pie, again made with Sorbitol instead of sugar. What I didn't realise, at the time, and I should have done, is large amounts of Sorbitol do have a pronounced laxative effect, and he did enjoy the cakes, but suffered for it afterwards.

# (7) And what did you do after your research post?

The money ran out, as it often does in research, for the MAFF contract I was working on, in 1981. I was married and living in Cambridge, at the time, and didn't want to move; my husband was settled there. So, I looked for a local job in Cambridge, and, in fact, they'd just started a new post for a community dietitian in Cambridge, and I applied for the job and got it. So, I then took on the community dietitian role. Now, at that time, it was actually a job share; I was working part-time. I was asked to take on organising mini-clinics for GPs, because diabetes had already started to become more of a problem. The hospital clinic at Addenbrooke's couldn't cope with all the outpatients it was seeing, and it was decided that GPs should see people with Type 2 diabetes in their own surgeries, and, as a result, they organised mini-clinics. So, one afternoon a fortnight or a month, each GP surgery would have a mini-clinic for diabetes, when there would be a GP with a special interest, a nurse, who would examine feet and this kind of thing, and as a community dietitian, I would go along to do a diet consultation.

### Did these GP clinics already exist in 1981?

These GP clinics were a new idea then. GP mini-clinics were a new idea, and it was the driving force of our local district community physician which meant that we'd set these up, and I think they were very successful. It certainly sharpened my interest in diabetes, and made me realise that it's a disease that's largely managed at home by the person concerned, and that doctors, dietitians and

nurses actually don't have much input, except for offering some advice.

What advice were you giving to patients in these GPs' mini-clinics, in 1981?

By 1981, there'd been a bit of a sea change in how people treated diabetes, and there was a move towards high fibre, high carbohydrate, low fat diets. So, exchanges were no longer used, in lots of cases. The emphasis was still on no sugar, so people with diabetes were typically advised to avoid all foods containing sugar, but they were encouraged to eat plenty of starchy carbohydrates, like bread and potatoes and pasta and rice. And around this time, the British Diabetic Association - now Diabetes UK - published the first nutritional recommendations for diabetes. And they did stress that a healthy diet for people with diabetes was low in fat, high in fibre, and at least half the plate should be filled with starchy carbohydrate. So, this was very much the ethos of the time.

And how much did you find that GPs knew about diabetes?

It was very interesting to see, in the mini-clinics, the majority of GPs who were running the mini-clinics were, by definition, interested in diabetes, so their knowledge was good for the time. You have to remember, during the seventies, nobody knew very much about diabetes anyway. We still didn't have many blood glucose monitors; they only started appearing on the market in the eighties, and we were mainly giving them to people with Type 1 diabetes. So, it was actually very difficult to assess what was going on. We had very crude tools, usually urine tests, so we couldn't really assess what was happening, and I think the drugs available for treatment, I only remember us using Metformin, Tolbutamide and Chlorpropamide, in those days, so there was a restricted choice of drug. Certainly the idea of cholesterol and blood pressure was almost never addressed in most of these clinics. The main ethos was diet, weight and looking after your feet.

How much do you think the patients benefitted from these mini-clinics?

My personal view of what the patients thought is that they liked them, because they knew the people involved, so every time they came to clinic, they knew who they'd be seeing. Lots of them had a personal relationship with their GPs, and they knew their practice nurse. Most of them felt they were getting better care, plus they were seen more regularly, so those who needed more support were able to get it; they didn't just get a routine six or nine month appointment, as they had been doing at the hospital. So, whether the standard of care was as good as it might have been at the hospital, I really can't say, but most patients preferred to go to their local GP for their care.

### (8) And what did you do after being a community dietitian?

In 1983, I had my first child, so, in those days, you stopped work when you had children; it wasn't really open for discussion. Some people carried on working, but most people didn't, after they'd had a child. So, I gave up work, and coincidentally, at the same time, we moved down to Kent, because my husband changed his job. So, I then had two children, and it wasn't until we moved to

Bath, in 1986, that I considered going back to work. By then, my oldest child was at school, and my youngest child was in nursery school. And I went to a coffee morning, and found myself discussing which were the best nappies to use, so I thought it was about time I went back to work.

And what did you do?

We were living in Bath, so I wrote to the dietetic department at the local hospital, and said did they have a vacancy, and, coincidentally, they did, so I was lucky enough to be given part-time work. They were very accommodating; I worked school hours only, so it actually suited me really well. It was a district general hospital, so, unlike Addenbrooke's, there were no specialities. There were a lot of outpatients, and I was mainly, again, dealing with diabetes, lipid disorders and obesity - those were my specialities - and the majority of work I did was in outpatients.

And in 1986, were there a very large number of people coming with diabetes?

They had a diabetic clinic every week at the hospital, and I think I had patients booked every ten minutes for four hours, once a week, every morning, so I'm guessing that's a reflection there were quite a lot of people with diabetes. The majority were Type 2, who needed weight reduction, but I still saw a percentage of Type 1s in outpatients. There was also an inpatient component to the job, at the hospital in Bath, and the consultant there - a Dr John Reckless - was very innovative. And he actually had a ward that was designated for people with diabetes, so if they were admitted to hospital and they had diabetes, they were put onto that ward. I think, as a result, they probably got better care. Certainly people with Type 1 diabetes got their insulin when they needed it, rather than when the next drug round was, and there was more attention paid to the kind of food they could eat. And if they ever had a hypo, there was always something available to treat it.

When you say they got their insulin when they wanted it, was it determined by their wants?

In Bath, I think it was very much to do with individuals and when they needed insulin. In many hospitals, still, insulin is given when the drug round takes place, regardless of when people are eating, and regardless of their usual insulin regimens. I think, on that ward, they took great care to make sure that didn't happen, so if people were taking soluble insulin with their meals, it was guaranteed they could get it at meal-times.

(9) Can we just do a little summary, then, of what dietitians were doing in 1986, because it's now sort of ten years since you first encountered diabetes?

By 1986, most dietitians, but not all, were no longer dealing in exchanges or grams of carbohydrate. The basic tenet was that of healthy eating: a high fibre, high starchy carbohydrate, low fat diet, with plenty of fruit and vegetables. More or less healthy eating, but with more emphasis on fibre. There was still, however, a great deal to be said about sugar. People were still convinced that sugar, in

all forms, was bad for people with diabetes, and under no circumstances should they be eating it. It made life very difficult, and in fact, I think in 1984, the British Diabetic Association produced a book called Carbohydrate Countdown, which gave people with diabetes an idea of how much carbohydrate was in the food they were eating. They divided the foods into red, amber and green. Green foods were healthy, so you could eat plenty of them; amber not quite so healthy; and red should be avoided, or only used as special treats. But still, the colour coding depended on the sugar content of the food, so, for example, in the green section we have salami, which is very high in fat, but actually contains very little carbohydrate, so people with diabetes thought they could eat as much salami as they liked. In the red section, it is almost, without exception, foods that are high in sugar or contain a lot of sugar. But interestingly enough, if we look back on it today, if we look at the green section, we've got muesli, which is high in fibre. An ounce gave the same amount of calories and total carbohydrate as an ounce of Coco Pops, for example, and yet muesli was in the green section and Coco Pops in the red section. So, the sugar content of foods really dictated how people thought about it, and, of course, what we know now is total carbohydrate matters more than whether it's starch or sugar. So, although I think most people would stand by the tenets of healthy eating, in terms of blood glucose control, it's total carbohydrate that matters, whether it's sugar or starch.

And what were you mainly doing, while you were in Bath, from 1986 to 1991?

By far the majority of my work was diabetes and obesity, and, by definition, a lot of the people I saw with obesity, also had Type 2 diabetes. I felt there was a lack of provision for most patients. The diet sheets we used were still the old style prescriptive diet sheets, where the dietitian would write out what the person was supposed to eat at every meal, and often gave it in terms of exchanges. So, I completely re-wrote the diet sheets, with the emphasis on the foods that would raise blood glucose level, but also some understanding of the fat content of foods, because that has an effect on heart disease. But even then, I tried to separate out the difference between healthy eating and foods which raised blood glucose levels. I felt, at the time, and I still feel today, that telling people with diabetes that they can eat as much starchy carbohydrate as they like, without informing them of the effects it's going to have on their blood glucose levels, is not productive.

(10) It's obvious, from what you say, that there's been a complete change in approach, from 1975, when you went on your placement at Addenbrooke's, to your time at Bath. Where was it that these changes were coming from? Where were you getting your information from?

I think, in retrospect, that's a difficult question to answer, but I think a variety of sources, and one of the biggest, I think, was personal clinical experience. Initially, in the seventies, we were really restricting carbohydrate. People still didn't seem to have the kind of blood glucose levels they wanted. Then we started suggesting they had a lot of starchy carbohydrate. People still weren't getting the blood glucose levels they wanted. So, it seemed as if there was something else going on

here, that just changing the diet probably wasn't having a fundamental effect that we thought should be happening. And it seemed to me, if we made that fundamental change from really restricting carbohydrate to suggesting people ate quite a lot of carbohydrate, that perhaps there could be another change too that might have similar effects, or not; who knows. But I think it was the fact that my patients weren't getting what they wanted from all these changes that we all found so frustrating. There were also quite a few dietitians, at the time, who I used to meet at the old Diabetic Association meetings, which were then held twice a year, and we would have discussions. And, in fact, a great friend of mine published an article entitled "who eats egg-sized potatoes anyway?" I'm not sure she was allowed to call it that, in the end. It was something like, you know "what is a ten gram exchange?", or whatever. But there was a feeling amongst a lot of dietitians, who were spending time with people with diabetes, that something wasn't right, but we weren't quite sure what it was.

How did the patients respond to your new diet sheets?

For a lot of patients, it was extremely challenging, because it seemed to be the exact opposite of what they'd been told last year, and it's something that I think dietitians are often criticised for, quite rightly, is that we're always changing our mind. Of course, as new evidence comes to light, I don't think it would be right to withhold it from patients, but I think it's probably the certainty with which dietitians say a lot of things that gets them into trouble! And so, the patients reacted... I think newly diagnosed, who hadn't had advice previously, were quite accepting of it, but those who'd previously restricted carbohydrate did find it quite difficult to be told "oh, now you can eat almost as much as you want". And, in fact, often they wanted to know how much they could eat. So, quite often people were using systems of household measures, so they would talk about things like slices of bread, or tablespoons of cereal, or tablespoons of rice or potatoes. So, some attempt was made to assess portion size by using household measures. So, for example, people still wanted to know, you know, what exactly can I eat? So, typically you'd start with breakfast, and say you can have two slices of toast, or you can have five tablespoons of cereal, or you can have one banana and one diet yoghurt. And then, for lunch, they could have two slices of bread, or two spoonfuls of potatoes. So, they were given choices. It was a bit like the exchange system, but without mentioning exchanges or carbohydrate. And it was an attempt to try and keep carbohydrate intake at moderate levels throughout the day, so they didn't have large amounts at one time; obviously that would have a huge effect on blood glucose levels.

#### (11) And what did you do after you left Bath?

In 1991, again, my husband changed his job, so we moved to Wantage, near Oxford, and we bought a very old house that needed a lot doing to it. So, I decided I wouldn't work, and within six months I was back at work! I think the choice of doing up the house and going to work was an easy choice to make. And again, I wrote to the local dietetic department, and said, you know, I was here in the district, were there any jobs available, and I was invited to a dietitians'

meeting. Now, in Bath, there were six dietitians for the whole area. I went to my first meeting in Oxford to find forty two dietitians in the room. It was a bit of a culture shock, I had to say. I was still very interested in diabetes, something that I felt that I was well versed in, and coincidentally, at the time I was writing, a research job came up working with Robert Turner and Rury Holman in the Diabetes Research Laboratories. And I went to the interview, and I was very lucky to be offered the job.

#### Where was that based?

In those days, the Diabetes Research Labs were based at the Radcliffe Infirmary, the old hospital in the middle of Oxford, which has since closed, and is sadly missed by all, even though it was falling to bits. And it was a really lovely place to work. And what I most enjoyed about the job was I was doing research, but with a clinical basis, so I was seeing people, seeing patients, giving them advice, but combining that with a research study too.

So, tell me about the research.

So, the first study I worked on was called the Fasting Hyperglycaemia Study. That was identifying people who didn't yet have diabetes, but who had higher than normal blood glucose levels. And we were looking at interventions to see if we could stop them developing diabetes. And my job was to give them diet and exercise advice, to try and reduce blood glucose levels, and prevent them getting diabetes. Part of this, of course, was weight loss; the majority of them were overweight. So, I was the lifestyle advisor; that was my job, and it was a really interesting job. The diet we were using, again, was the healthy eating approach: low fat, high fibre, fruit and veg, but with an emphasis on portion control, because we were looking at weight loss, and we were also encouraging physical activity. For most people who were sedentary, this just meant walking more, but we did aim to get them to exercise for at least three times a week, for forty five minutes at a time. And they had to exercise so they felt their heart beating harder than normal, they were breathing slightly heavier, or they were sweating slightly, so they felt they'd done some activity. And we saw people at monthly intervals, and the study actually lasted six years. And what was really interesting for me was, everybody who saw me lost weight in the first three months, but by the end of the study, everybody was back where they'd started. And I found that so interesting, and it made me think about not the advice we give people - i.e. what we say - but how we say it. Was there another way of delivering information that would make people make changes in their life that they could maintain?

(12) How much advice had you given on physical activity before you'd started this research?

The main advice I'd given to people, in the past, had been about dietary change. I think I may have said in Bath, on occasion, "oh, and it might be a good idea to do a bit more exercise", but that was about as far as it went. But there was growing evidence, now, that physical activity really made a difference, in terms

of preventing diabetes, and so we did pay a great deal of attention to that. It was something I was actually quite interested in, and I have to say, as a result of doing the study, I increased my own physical activity. So, it might not have worked for the people I saw, but it certainly worked for me. And I think it was something, again, that just reinforced what I felt about dietary change: that everybody has the knowledge. If you ask most people what they need to do to increase their physical activity, they'll tell you. What they can't tell you is what needs to change in their life in order for them to be able to make these changes.

And that, perhaps, links up with what you were saying about the way you tell people about things, rather than just the content of what you say.

Yes, about that time, a colleague of mine, Liz Eeley, was working on the United Kingdom Prospective Diabetes Study, or UKPDS, which, of course, Robert Turner and Rury Holman devised, and ran very successfully. And we both felt the same thing: we both saw that initially people were capable of great change. especially when they'd just been diagnosed with diabetes, but maintaining that change was really impossible, and that quite often, if we went on at them, as we sometimes did, all we seemed to do was create resistance. And this led to my interest in behavioural approaches to changing lifestyle, and not just looking at what people were doing wrong, which is what you're taught to do as a dietitian. You take a diet history, you find out what they're doing wrong, and you tell them how to put it right. But you don't need to do that. Actually, most people have the necessary information. Most people, nowadays, know what they have to do; the difficulty they have is doing it. So, I'd changed my consultation style quite dramatically, during this time. Went on a lot of courses - Charles Fox runs an excellent one in Northampton, which looks at exactly this - and it's about supporting behaviour change in people, and not telling them what to do.

How do you support behavioural change?

The idea is to look at how confident people feel about the changes they can make, look at the barriers, discuss what past experience they've had, so it's an exploration of feelings. I think what's largely overlooked in a lot of the advice we give people is, how people feel is what drives their behaviour, and if you can explore how they feel, and look at what's stopping them making changes, that often helps them make the change.

Can you give some examples?

Well, I've started running weight management groups, now, for people on insulin. They do find it very difficult to lose weight. I run it with a clinical colleague, Angela Hargreaves, and we spend the first week exploring barriers to change. So, for example, some people will say they can't exercise because they're too busy-you know, they work full-time, they get home, they have a family to look after, there's no space for them to exercise. So, we have a full discussion about that, and often you can find out that they can always make space for stuff they want to do, for example, a lot of people have no difficulty in finding half an hour a day to watch a soap opera. That's not an issue for them; they want to do it, so they

arrange their lives so they can do it. We go through the process to find out what it is they do to make sure they have half an hour to do what they want to do, to see if they can use those same techniques to, for example, take exercise. They don't necessarily have to go and join a gym or go swimming or run a marathon; for some people, just walking a bit can make a difference. But it's trying to put people in the place where they're identifying what their barriers are, and they're also providing the solution.

### (13) Can you give some examples of people who manage to change their lifestyle?

Yes, I certainly can. I'm thinking of one lady in particular, who, although she didn't have a binge eating disorder, was quite frank about the fact that during the evening, she ate too much. Her background was: she was a busy mother, and her husband was very demanding, she did a lot of paperwork for him at home, did his accounts. And in the evening, when she sat down, once the children were in bed, that was her time, but that was also the time she just used to sit and eat. Now, she used to watch television, she liked ITV, and she wouldn't miss her programme, but every time a break came on, she was into the kitchen, opening the cupboards, finding what she could eat in the fridge. And what we used with her is a technique called problem solving, where she identified what the problem was - she knew what it was - that every time a break came on the television in the evening, she would go and get something to eat. She wasn't hungry, she didn't need it, but she felt she was treating herself. So, we made a long list of what she could do to stop this, and we just went straight through the list without evaluation. So, we came up with ideas like, for example, lock the kitchen door, put a lock on the fridge, don't buy any food, stop watching television, change to BBC. There were a long list of things we could do, and once she'd made that list, we went through it one by one, deciding what would suit her. And, in fact, half way through, she said "oh, I could take up knitting", and by the time we'd worked through the list, she decided if she took up knitting, then that would work very well for her, and that's what she did. Now, I'm not saying knitting helps you lose weight. I'm saying for her, this was a solution that worked. I've got two nice jumpers to prove it works, and she managed to lose a significant amount of weight. But it was because she identified a solution to her particular challenge.

## Any other examples?

In our weight management group, we also have people with Type 1 diabetes. And I'm thinking specifically of a man, now, who used to snack a lot, so every morning and every afternoon, he had a snack. Now, when he was first diagnosed, thirty years ago, he was encouraged to snack, but with the new kinds of insulin, people don't need to snack, and often can manage on just three meals a day. And he just snacked out of habit, and, of course, he enjoyed it; it was a time when he felt he could sit down and have a nice cup of coffee, a chocolate biscuit, or a banana, or a packet of crisps, and he thoroughly enjoyed it. He had identified that if he stopped the snacking, he would probably lose weight, so we had a big discussion about how he could do that. And he was still convinced that he

snacked because he needed to, so what he decided to do was just test his blood glucose before he snacked, and make a decision then. And he was astonished to find that his blood glucose was actually quite reasonable mid morning and mid afternoon, so this perception he had that he needed to snack just wasn't true. So, he tried not snacking to see what would happen, and, in fact, found that was very successful. And on the occasions where he felt his blood glucose was too low and he needed a snack, he would just have an apple, and he found, to his astonishment, that worked as well as a chocolate biscuit or a bag of crisps. So, for him, it was more an idea of challenging the perception he had of needing a snack. The enjoyment was very interesting, because he'd said, initially, he had the snack because he enjoyed it, but it actually turned out he was having it because he really felt that he needed it. And he found it very challenging, when he decided to do this, but also, it made him think about the way he acts towards his diabetes, and how he'd turned... At the end of the month of the course, he did say that he'd stopped blaming his diabetes for a lot of the stuff that was going on in his life, and again, he successfully lost quite a lot of weight.

(14) You became interested in behavioural aspects of your work in the early 1990s. What major changes have there been for dietitians since the early 1990s?

Since the early 1990s, I think there's been a recognition that dietitians can't just dispense advice about what people should do, that they should address motivation and behavioural approaches to changing lifestyle. And I think most dietitians accept that when they're working in chronic disease, the traditional medical model doesn't apply. And most dietitians, I think, now take this on board. This is also true of a lot of nurses too, of course; it's not just dietitians. And there's a recognition that diabetes is largely managed by the person with diabetes, and what those people need is help and support and motivation. They don't need to be told off, or told what to do by the health professionals that they see. So, I think it's a shift, not in the kind of advice we give, but in how we deliver it. And certainly, during the late nineties, when I was working as a specialist dietitian in a clinical role. I think it's true to say I developed these skills further. I changed my job again in 19... I'm sorry, I mean 2004. In 2004, I changed my job to become a research dietitian, which gave me a bit more space to look at the stuff I was really interested in. And, of course, in 2003, what used to be the British Diabetic Association, is now Diabetes UK, had published updated nutritional recommendations for the new millennium. And I think most dietitians were really pleased to see the emphasis is now on treating the individual, respecting their culture, the choices they make, their preferences. And this individual approach, I think, has been a great benefit for people with diabetes. There was also, at the same time, a growing awareness of people with Type 1: that strict prescriptive diets were ineffective; that there was no reason people with Type 1 diabetes can't eat exactly the same things as people without Type 1 diabetes, if they were able to match their insulin to the carbohydrate they ate. And, of course, a lot of centres now run courses teaching carbohydrate counting and insulin adjustment; the best known, of course, is

DAFNE, but many centres run their own courses. We run one in Oxford called InSight, and we were very lucky to get funding from Diabetes UK to run this as a research project. And I consider myself really fortunate for being able to deliver it clinically, but also evaluate it in my research post. And we've just recently presented the results at Diabetes UK, in 2008, which show that it's an effective programme that improves quality of life. And it's nice, now, to have the evidence that shows that what we're doing is effective.

How possible is it to get everyone with Type 1 diabetes to go on such a course?

I think it's important to remember that people with diabetes should have choices. I don't think the structured education courses are suitable for everybody, and certainly if people aren't numerate or literate, it can be very challenging to complete these courses. There are also some people who just aren't interested; they're quite happy eating similar foods everyday, and taking similar amounts of insulin. To suggest these people would benefit from a course, I think, is not right. Our attitude, in Oxford, is that these education courses should be offered to everybody, and that's what we do; it's now part of our Care Pathway. So, a year or so after diagnosis, people with Type 1 diabetes are offered this course, but it's up to them whether they choose to attend or not.

Their Care Pathway sounds like a bit of jargon. When did that phrase come in?

Care Pathways, I think, have been around for a few years, now, and they're very simple little algorithms that say: at diagnosis, the patient with Type 1 should receive, for example, an insulin pen, some insulin, advice on how to inject insulin, advice on how to measure their blood glucose, and simple dietary advice. They should then be seen at certain visits, and at each visit the following topics should be covered. And by the end of the first year, they should be offered the chance for an education course. So, yes, Care Pathways is a bit of jargon for us making sure that we cover all the things that need to be covered, for people with diabetes.

# (15) And what advice is being given to Type 2 patients?

I think we've moved away from this idea that Type 2 is mild diabetes, and certainly, the publication of UKPDS, in 1998, showed us that it's not a mild disease. For example, 50% of people with Type 2 diabetes already had some kind of tissue damage associated with diabetes, at diagnosis. We know diabetes is the leading cause of blindness in the UK, in people under the age of sixty. So, we know it's not a mild disease any more; we know that it really matters. And people with Type 2 should receive treatment and structured education, similar to that given to Type 1. And, in fact, in 2005, Diabetes UK and the Department of Health produced an edict saying that all people with diabetes, whether it's Type 1 or Type 2, should receive structured education. As a result of this, a randomised control trial called DESMOND - and can I remember what that acronym stands for, no I can't - is offering structured education to people with Type 2 diabetes. And here in Oxford, we don't run DESMOND, but we do run our own programme called Diabetes Together. So, all people diagnosed with

Type 2 diabetes are offered the chance to attend this structured education course. Again, they're given the chance to attend, they're not... it's not mandatory, so it's their choice whether they attend or not. But I think the take-up of this course is actually quite encouraging; it is well attended, in Oxford.

How has your work been affected by changes in the Health Service?

The big change in the Health Service, I think, came with the QOFs - the Quality Outcome Framework - where GPs were paid by results, and they were encouraged to take on care of people with diabetes, and are paid well to do it - there are a lot of QOF points for people with diabetes. So, for the majority of people with Type 2, most of their care now takes place in primary care. And the knock-on effect we've had at the hospital, of course, is that we now see very few people with Type 2 diabetes; certainly no newly diagnosed. We'd see Type 2s who may need to go onto insulin, who need specialist help to lose weight, or who already have some kind of tissue damage associated with diabetes. But the majority of people with Type 2 diabetes are now seen by their own GP in primary care, and, of course, sometimes they get excellent care, and sometimes they could get better care at a hospital. It really depends on the individual GP.

And what have been the major changes, in your experience, as a dietitian?

The biggest change I can think of, over the past twenty years especially, is this move away from an isolated dietitian, sitting in an office, somewhere, seeing someone with diabetes completely independently, to working as part of a multidisciplinary team. And that's made a huge difference, mainly because patients are getting a similar message from all members of the team. It must be terribly confusing for people with diabetes to get different messages from different healthcare professionals. But also, it means a broadening of knowledge for everybody concerned. So, for example, I couldn't run InSight unless I knew about insulin adjustment, and the nurses I run InSight with have to know about carbohydrate counting. And I really think this getting the full picture has made a big difference to the way we practise.