

95. Barbara

(1) Tell me about your background.

Okay. I'm one of five children - I'm actually the second youngest - born in Burton on Trent, in Staffordshire, in 1968. Fairly quiet upbringing. My Mum was from Barbados, my Dad was from Jamaica. They came over in the fifties; I think the late part of the 1950s. My Mum trained as a nurse; she was an enrolled nurse, and she trained in Somerset, then came up to Burton. I think she had a stint in Derby hospitals. My Dad worked in the power stations in Staffordshire, and worked in various places like that, really. From as much as I know, you know, I can remember, he travelled out to Derby, and one of the power stations he worked at was at Drakelow power station. So, as far as I can remember, that's where he worked for most of his working life. I went to the local primary school, which was a five minute walk - Victoria primary school - which was uneventful; lots of friends and things. And then had a comprehensive education - secondary education, as they called it then - and then went to first year of sixth form. Moved on to technical college for a year, had a few... six months out, or so, deciding on what I wanted to do. I think I originally wanted to be a school teacher or a physical education teacher, or something like that, and then decided I wanted to go into nursing. And I came to Birmingham, in 1988, to start my nurse training at the Queen Elizabeth Hospital.

Before you started your nursing training, did you know anything about diabetes?

Not really; I can't remember that I had. I mean, I did learn later that my grandparents, on my mother's side, had diabetes. But no, I did know very little, because my Mum, she worked in elderly care, predominantly, working in rehabilitation, I think, especially eld... yeah, it always was elderly care, and she used to work in nursing homes, and things. And to be fair, I don't think she really spoke much about her nursing, and we didn't really ask. And one of the funny things is, really, I didn't actually want to be a nurse, I just actually drifted into it. I mean, people say something about a vocation. I don't know whether it was because I didn't think I could do anything else! But my mother must have had something to do with it; some subliminal messages, or something.

(2) And tell me about your nursing training.

Okay, I started my nurse training in 1988, and it was a pilot study, as far as I was aware. We did the first year on the wards, and we went through... most of it was hands-on, really; didn't do a great deal in the class work. There was a lot of assessment on... with mentors, and things, within the ward areas. And also, we did have quite a lot of responsibility, during the training: had our own sort of bank of patients - obviously being supervised by the trained nurses, but it was very much a job. We did night shifts, and I think, actually, I think I probably did night shifts on my first ward allocation, and they were quite long allocations, actually. And I really did enjoy it, but it was very worrying, as well, because we just got... not thrown in, but hands-on straight away. And I think that if that didn't put you off, then nothing would, and, you know, I'm still

here, so it's a bit of a testament. Anyway, so the first year we did two big ward allocations, and I did those at the Queen Elizabeth Hospital, which was, as we all know, specialist in its field. So, did something like renal - patients with kidney problems - and general medicine, and surgical; that was very interesting. And then, in the second year, we did all our specialities, so I did sort of elderly care, did the children's hospital. Some of my colleagues, they did mental health within hospitals, but I actually went out and was community based, so the experience was extremely varied. And then, in the third year, we went back to sort of fairly long allocations, and I think it was preparation for us, really, to decide where we would like to be. And I basically ended up on a female medical ward as my last allocation. And within that third year, it was very much preparation for going out and hitting the ground running, you know: being in charge on night shifts, and being in charge of day shifts as well. Just doing your management role, really; a thorough grounding for when you qualified so that you could go straight into the role. And we did, throughout that time, also did assignments and things, and obviously we had to pass those assignment, and a written exam at the very end, to qualify. But, as I said, we were part of a pilot, in between sort of diploma and a degree, because the year after that, it was very much needing to get a degree to actually become a nurse, really.

So, yours is a record of possibly a unique training, different from the diploma and different from the degree?

I would think so, and from what I can remember - and I might be wrong - they piloted it for... only piloted it, this particular scheme, for a few years, because it was just before... I think was it Project 2000, because they went into Project 2000 after that. And then, very quickly, went into the degree, because, actually, I think they wanted to ensure that nursing was seen as a profession. And to enable us to become a profession, you needed to go through some structured form of education, something that was recognised, and that's where the degree came in.

(3) Did you come across any patients with diabetes, during those three years of training: 1988 to 1991?

Yeah, there were patients; I think, predominantly, patients who had sort of Type 2 diabetes, who were on sort of tablets and things... sort of, they were controlled on tablets and things. And I suppose, at that time, I really didn't pay much attention, because, you know, you had patients who came in with strokes, or patients who'd got other difficulties, you know, come in with pneumonias, and just the general things that came through on a general medical ward. And yes, there was like... you remember going round and doing their BMs, as we used to call it then, and doing their injections, and making sure they had 'a diabetic meal'. And they would all get their meals first and their medication first. And waiting for their blood result to come up on the machines, because they did take quite a long time - I mean, I can remember, was it two minutes? And also, being worried about jabbing the patient's finger, 'cause we haven't got the devices that we have now. And we used to use something that looked like a

lancet, really, and you used to psyche yourself up to like stab their finger with it. And then you'd worry that you get enough blood, because you'd got to get lots of blood on it. And then you have to wait a minute, then wipe it off, and then read it against a chart, and, you know, make sure that you get the results right so that you can get, you know, give them the right amount of insulin. And, you know, drawing it up out of the vial, you know: which one did you draw first? Or getting it right, because the marks were so small. And, like I said, waiting, letting them wait the optimal time before they could eat, and then fitting that in with everybody else that's on the ward. And also, the other thing was, say a patient had... their toenails needed cutting, and they're diabetic, and it was like "no, no, you can't do it, because they've got diabetes". But I don't think I really paid much attention, 'cause they were just on... you've got a thirty bedded ward, and so, therefore, you know, you look after each individual patient for their individual needs. But, I mean, I do remember those aspects of diabetes at the time.

- (4) And now, twenty years on from when you began training in 1988, what do you think of that kind of largely practical training that you had?

I actually think that it was a very good thing, because you have to realise that you take on three years' training, and like most of us, we didn't know, actually, what to expect, what was expected from us. And knowing, now, that we were very much part of the numbers, although they say that, you know, you're supernumerary for a period of time, so you're observing, but there's only so much that you can actually observe. And I think, in order for you to make the right decision about what you're doing, whether you think it's the right thing for you, I think you have to get stuck in. Obviously, you've got to get the balance between supervision and taking on things that, you know, you're clearly not ready for, but I think, personally for me, that experience was the right thing for me. And the long allocations also allowed you, really, to get stuck in, get to know the team that you work with, get to know the patients, understand what your job actually was. Yes, they were worried about it, and there was some trepidation about it, but I think it gave you a good thorough grounding. However, I did listen to some people about their training, previous to mine, and those were even more hands-on, they had even more responsibility. So, I think, I suppose, that was a bit of trying to get the balance right for you.

So, it was good for the nurse in training. Was it good for the patients who were trained upon?

I think so. I mean, you always had a qualified member of staff there, and they wouldn't let you... I mean, they were always looking at you, watching you, and they were aware of your abilities. And I think, in a lot of respects, they would only ask you to do the things that they felt you were capable of. And then, actually, the thing is, the patients were very good. They knew we were students, because obviously we had our blue uniforms, and our stripes on our hats, as well, so they knew at what level we were. So, one stripe for your first year, two stripes for your second year, three stripes for your third year. So, I

think they actually knew, you know, what you were capable of, although they didn't seem to complain if they had students looking after them - not that I can remember, anyway. And I don't think it was too bad. I think it meant that it improved the quality of care that they had, because we were quite a big training hospital, so we had a lot of student nurses on the wards.

(5) What did you do after you qualified in 1991?

Well, when I qualified in '91, I actually got a position as a staff nurse on the ward of my final... in my third year, which was a female medical ward. And it was a very good ward, because, I mean, I got to know everybody's team, the doctors, and the speciality, really. You got... there was a mixture of medical conditions coming through. We had a very... various age ranges also. People coming in who were paraplegic, who needed, obviously, feeding with NG tubes, and pressure sore care; and young people who'd had strokes and in wheelchairs; and, you know, foot ulcers; and all... just a big mix of patients. And I would say that... I mean, I came across diabetes within that ward as well, because, to be honest, you would get people who had chronic illnesses. I mean, I can remember somebody who had a condition called Bronchiectasis, and they had difficulty breathing. She also had diabetes as well, and so she had... when her diabetes was uncontrolled, she would... I mean, she would be put on steroids for her condition, and then her diabetes would become uncontrolled. So, it was a bit of a vicious circle for this lady. And I got to know her very well; she was in for months. And, initially, she was being controlled on tablets, and obviously, when she had a flare up of her breathing problems and she was put on sort of steroid treatment, she ended up going on to insulin therapy to actually manage her condition, at the time, also. So, I used to see her quite regularly. And her treatment would change, so from... going on from, say, just taking a tablet for her treatment, she would then be on insulin, then we'd get her breathing better. And unfortunately, at one point, she didn't revert back to tablets, she stayed on insulin, and so we had to manage her through that, with the help of, obviously... we had ward one, at the general hospital, then. And that was actually the diabetes ward, and that's where the nurses were who actually delivered the education for those particular patients who had diabetes. So, if the patients... when the patients were well enough, they would actually go down and stay the day on this ward, or if they were newly diagnosed, they would actually stay down in the unit, and they would have them there for five days, or so. So, they'd have them from when they were acute to then when they were feeling better, and then when they were managing themselves. But our patients came in, predominantly, with conditions that were probably not associated with their diabetes. We would treat them for that, but then they would have input from that particular ward.

The nurses on that specialist ward downstairs were educating the patients. Did they have any role in educating you?

From what I can remember - and it's fairly long ago - I mean, I think they would come in and they would talk to us about it. If we had a patient, then they'd tell

us what treatments they were on, and what they'd given them to use, you know, to manage their condition. Not so much as... I mean, if I relate back to now, what happens now, and it sounds terrible, but I can't remember the input that they actually had, at that particular time.

- (6) So, in your first job, as a general nurse, how much did you know about control or about insulin, when you were dealing with patients with diabetes?

I think, thinking back now, I didn't know a great deal. I knew about when a patient became what we call hypoglycaemic, so they start acting odd or sweating or shaking, and things, and knew what we needed to give them, although it's not the right thing to give them now. We used to give them things like chocolate, or dissolve sugar in milk, and try and get that down them, to drink that. And we knew that if the sugars dropped below a certain level, or, on the little reagent stick, if it was like less than... oh, what colour was it now, I can't remember. Was it green or something? If it went below that level then we knew that they might be having a hypo, even if they weren't having symptoms, so we'd be giving them lots of sugar, and things like that. And we knew when it was too high that we'd get the doctor in to give them some additional insulin, if that was what was required, or for them to adjust their treatment on a day to day. But normally we'd be giving them extra insulin; they'd give them like a one off shot, and then we'd be told to sort of monitor... not so much... I mean, most of our patients, I can remember, I think most of them we used to test their urine. It's only sort of later on... I mean, I can remember, on that particular ward, we did have reagent strips that we could test their blood, because I know we had to wait two minutes - a minute, wipe it off, then wait another minute - and then read it against a strip. Now, I'm sure we had those on that ward, at that time.

But you can remember urine testing as well?

I can remember, yeah, urine testing, because the majority of them, yeah, we would test their urine for glucose, and then, obviously, that would be something we'd put in... document in our nursing notes. And if, obviously, they're continuing to have glucose in their urine, then we'd speak to the medics. And we'd also look at what they had on their lockers as well, 'cause, obviously, some people would be eating a little bit more than they should do. And I don't even remember... I mean, it was more we would be looking at whether they were just eating sugar, chocolate and biscuits, and stuff like that, and obviously making sure, when we ticked their menus, that they had a diabetic meal. And I think I can remember dietitians coming up and giving them their menus, telling them what they can and they can't have, and letting us know what they can and can't have, yeah.

- (7) What can you remember about administering insulin, in the early 1990s?

Well, I can remember we definitely used to give it via a syringe, and used to always make sure that we check it - and which is normal practice, I think, now, still - that we used to check it with another member of staff. And they used to have it at certain times, at set times during the day. And I can remember

that we had patients on either a... some patients were on sort of a mixture of cloudy and what we call soluble insulin, and we used to ensure... had to make sure that we drew it up in the right order, and made sure that it was, sort of, took it out of the fridge and drew it up, and put it in the right order, and then gave it to them. I can't actually remember allowing a patient to inject themselves, at this point - probably did, but I can't be shaded, because it's been a long time ago. But it was definitely they had their insulin, generally, at sort of breakfast time and at evening meal time. There wasn't... I can't remember patients having lots of injections; only those that say, for example, needed an extra insulin injection, because their sugar levels were too high. But normally it would be breakfast and evening meal, and generally we would test their blood glucose levels... test their urine levels, really, more often than testing their blood.

Do you have any memories about their diet, or not?

I can remember there were exchanges, and they had diet sheets, and I remember the menu sheets coming up said "diabetic menu", and ensuring that they had... It was usually they'd have like their carbohydrate - small portion of that - and I remember they used to have the tinned fruit or sugar-free rice pudding, or all of those sorts of things, that always looked different to the non-diabetic meals, that I can remember. And then, like I said, they had their exchange lists, so some patients were only allowed to have a certain amount of carbohydrate at breakfast, a certain amount of carbohydrate at lunch, and a certain amount of carbohydrate at evening meal. And also, they would have... their snacks would come up on the trolley, as well. So, they would have like something mid morning, and then make sure that they had something just before they went to bed at night, to ensure that they wouldn't go hypo. Yeah, I can remember that; they always used to have their snacks.

(8) And what did you do next, after being a staff nurse at Birmingham General Hospital?

Well, South Birmingham, as it were - it was health authority - we actually merged, and they moved us all to - redeployed us, actually - to Selly Oak Hospital, which is University Hospital Birmingham; it's had so many name changes. We were moved out of the General Hospital, and then the General Hospital then became Princess Diana Children's Hospital, something like that. So, we moved our ward, lock, stock and barrel, over to Selly Oak, and sat us on the end of a female medical ward. So, we were sort of trying to work independently on there, for a while, and then we merged, basically, because it wasn't very practical for us to be two separate wards on one ward. And I worked there for, I would say probably for about a couple of years, really, as a staff nurse, and then moved to another mixed medical ward within the same hospital, as a slightly higher grade, as an E Grade staff nurse. And this was also, sort of like, a twenty eight bedded mixed medical ward with a... had a little bit more responsibility; sort of being in charge during day shifts and night shifts. And just very much the same: looking after patients with chronic illnesses, who've come in with acute

episodes of their chronic illnesses, and treating them for that, and a little bit of rehabilitation as well. And then I did... I worked on that ward up until I became, basically, became pregnant with my first child in '94, and then I had her in '95. Came back onto the same medical ward, and worked there for a while. In fact, because I had a young daughter to look after, I actually worked the majority of my shifts as nights, which was incredibly unsettling for me, because my body clock really didn't function right. And it's a different type of nursing. And I know it's twenty four hour care, and I know that patients are asleep for the best part of it, but I found it could be... it keeps you on your toes, in the sense that you don't have as much of the medical team around at a time, and so, if you have an acute problem overnight, it seems ten times worse.

- (9) And then, during 1995, when I worked nights - and the beginning of '96 - there was a realisation that perhaps I can't continue to work nights for the rest of my life. And also, working days and night shift doesn't really... is not good for life, really. And I knew of a colleague, who was talking to me one night, and said, basically, there was a position going on the diabetes ward. And I was very interested in diabetes, at the time, because what I found was that the majority of the patients that I actually worked... looked after on the medical ward had diabetes, although it wasn't their presenting condition, or it wasn't the reason why they came into hospital. But they still had this condition, and it had a sort of an impact on their lives. And the other thing is - and I have to say, it's not particularly just because I like diabetes - it's the fact that this job was Monday to Friday, no nights, and no weekends. So, I applied for this position, and I was successful. And in 1996 - the summer of 1996 - I actually worked at the diabetes centre - which was in the same Trust, on the same site - as a diabetes nurse educator, which was very different from working in an acute medical ward. It was very... had time to build up relationships with patients, you had your own case load, and predominantly the work was that of education, both for the patients and for their carers, and the medical multidisciplinary team. So, assessing these patients who had diabetes, and looking at their educational needs, and looking at what they needed treatment-wise, really. And it was ongoing. And I also found that I see patients now, who I looked after then, when I was very green, really. And they can still remember me, and they also can remember my various going off on maternity leaves and things. And, you know, it's almost like a family, it is, because you get to know them very, very well, and also through the progression of their disease. So, although we didn't see... Ideally, we do see patients who were diagnosed as having diabetes, and controlled on sort of lifestyle interventions and diet. And we would probably, at that particular time, see them for a one-off, for educational sessions, but most of those would be referred back to what we would call primary care, or back to their GP care, so we wouldn't see them. But, funnily enough, I then would start seeing them later on in the progression of their condition, as they went onto tablets, or as they got re-referred back to our clinics,

and then as they went onto insulin, or as they developed other conditions related to their diabetes.

- (10) So, you were working as a diabetes nurse educator, but what specialist education in diabetes had you had yourself?

At that point, only my experience within working with patients in acute medical wards, and the odd, sort of, one day or two day course. But obviously, when I came into diabetes, as part of professional development, they would look at - and talking with my manager, and looking at the gaps in my knowledge - I was then put on courses. I did a five day multi-professional course in diabetes, and I was actually... and it wasn't just for diabetes nurse educators; it was actually for practice nurses, GPs. So, I got quite a good insight in how diabetes was actually managed, at that particular time, both in what we would call secondary care and primary care - and I know that they're changing those labels as well, but that was as it was at that time. So, I did a lot on physiology, a lot on sort of epidemiology, about the treatments, et cetera, the conditions in diabetes, you know, the coronary heart disease, retinopathy; all the complete package with diabetes. So, I did that, initially. I had, obviously, in-house training and assessments. Also did the diabetes nurse... the 928 diabetes nursing. I also did a teaching qualification in college, because, obviously, a lot of our work, as a diabetes educator, revolved round delivering education. So, I did my stage one, stage two, 730, teaching... adult education. Also attended conferences, so Diabetes UK conferences, a counselling course in diabetes, and lots of one and two day education packages, to the stage where I was actually starting to sort of teach on the developed courses that we did within our area. And I've recently done a non-medical prescribing course, because our job has changed quite significantly from the time that I actually trained as an educator. And our role and our title has also changed. Well, initially we were diabetes nurse educators, and then, two years later, we became DSNs, or Diabetes Specialist Nurses. And then I went off on maternity leave in sort of 2005, as we were going through the Agenda for Change. So, Agenda for Change was looking at re-banding all nurses - not just specialist nurses, but from healthcare professionals, anybody, actually, who worked within the NHS, they wanted them all to have particular bands based on their job description. So, after we were banded, it was then decided, because of the way in which we... our role has developed over time, that -we would then become Clinical Nurse Specialists in Diabetes.

- (11) You mentioned going to the Diabetes UK conference, and other courses concerned with diabetes. Out of interest, did you meet many other nurses from a Caribbean background?

Funny you should ask: no, you don't, really. I mean, that surprised me, in a sense, that I was very much, I would say, a minority within the speciality. Within our Trust, there is just me, actually, as a diabetes specialist nurse. And I've been to conferences in London and Glasgow, and I would say that no, it doesn't appear to be a speciality that we tend to go into, whether or not we specialise in any field, at all. In Birmingham, we have, I would say we have four... probably



about four or five diabetes specialist nurses. And that's been growing, and I don't know whether or not it's a representation of the type of population that we actually have here, as in similar places, such as London, I've seen two or three. But I don't know if I could speculate. I mean, my Mum, as well - she's no longer in nursing, although she would have retired by now, but she retired fairly early - and I suspect that I don't see many of her age in any field such as this.

And yet, among patients, there's quite a prevalence of diabetes among people from a Caribbean background.

Yes, there is. And of recent years, I've noted that, perhaps, we may not be offering them the - I would say - culturally specific care that they actually need. I used to belong to a Afro-Caribbean help group, who actually looked into diabetes and hypertension. Now, that was back in 2003, and we actually set up a health awareness day, but there's been nothing since that, really.

- (12) However, I've noticed, I mean, there is a high prevalence of diabetes within Afro-Caribbean groups, as well as Southern Asian groups, as well. And there appears to be a bit of a shift, in a sense, that we do look at that - culturally specific education - for those groups of patients, and there is a lot of resources out there, all in different languages and things, and I've been part of a group who've organised particular events. And I've actually noticed, within myself, that I have an interest in looking into what is needed for our Afro-Caribbean patients. I think, actually, talking on this oral history, it's made me actually think about what I can do, as somebody that comes from an Afro-Caribbean background. Whether or not I can pick up where I left off in 2003, and see whether or not there is a need to develop something that is culturally specific, and see whether that actually makes a difference to the management of patients... Afro-Caribbean patients with diabetes.

So, when you were talking about recent culturally specific work, you were referring just to South Asians, then?

Yes, there is. And there is a group they've got; I can't remember what it's called. It's called FAD, and they've worked very closely with Diabetes UK, and they've actually produced a DVD. And there's also been quite a lot of research into how... delivery of the education packages: how does it work? How does it work best? And that's an ongoing... Some of my colleagues are involved in that, so that's an ongoing thing.

So, there's ground to be made up, then, for people who have, say, a traditional Caribbean diet?

I think there is. And I found it very interesting, when I was working with the group in 2003, based in Aston. And when we did the health awareness day, what I actually noticed was that there's still this feeling that diabetes, if treated with tablets or just diet alone, is classed as mild diabetes. Unfortunately, it isn't. It needs to be treated as effectively with oral diabetic agents and exercise, and

other lifestyle interventions, at that stage, because it's very much silent, then, and that's where the damage is being done. And I think we need to... need to be more education in that, highlighting it, as well. And also, looking at people who have pre-diabetes, or people who are at risk of diabetes, so we can actually put interventions in that can actually prevent it, or slow down the process.

(13) What kinds of things would you like to say to patients from a Caribbean background?

I think... I mean, we're very renowned for our cooking, in the Afro-Caribbean population, and we like what we call our hard foods, so our yams, our bananas, our plantains, and things. And I'm the same: frying our fish and cooking our mutton, and things like that. But I think what we need to look at is different ways in which we can cook our food, and portion sizes, because I've been down to my mother's on a Sunday, and I've had my plate piled high with my rice and my yam and my banana, and we're forgetting that this is all very starchy food. And we all love our fried plantains, and things like that. Perhaps what we need to do is consider, if we're going to have our plate full of food, is reduce our portions. I mean, at the moment, it's 40% carbohydrate, and I would think most Afro-Caribbean people would have about 75% of starch on their plate. So, thinking about cutting portion sizes, cooking foods differently - instead of frying their plantain, grill their plantain, boil their bananas, as they do - don't add as much fat. And if you do have a nice cook-up on a Sunday, perhaps go for a nice long walk afterwards, a good thirty minute walk, and just think about cutting out the fatty foods and looking for alternatives. We still can be culturally aware and have our culturally specific foods, but perhaps we need to, as I said, cook with less fat, eat less of it; that's a good start.

Are there any other messages that you'd have?

I would say, from personal experience, and talking to other family members that I have who have had diabetes, is that just... I think, treat your diabetes with respect. There isn't such a thing as mild diabetes. It all needs treating with something, whether it's the diet and the exercise, whether it's the tablets, and whether or not you have to go onto insulin, because we're finding that, you know, the tablets aren't doing what they're supposed to be doing. I mean, diabetes is a progressive condition, and a lot of Afro-Caribbean people do have it, predominantly the Type 2 diabetes, which is, you know, you see people... that you're slightly heavier than you normally are. It tends to be due to what we call insulin resistance, you know. If you need to change your treatment, find out as much as possible about the particular treatment that they want you... put you on, so that you can use it to the best of your... you know, to benefit you, because the treatment is required, it is very important. And if you have to have insulin, I know it's not very nice, needles aren't very nice, but that insulin will allow you to improve your control. And even if you don't feel unwell when they decide to change your treatment, that doesn't mean that your diabetes is okay. It's very silent, it's causing problems, long-term complications. You have to remember, you don't have to feel or experience symptoms to be having the

complications of diabetes. And I think that's something that a lot of people from this sort of culture don't actually realise. If you're feeling well, it still means that you do need to have your treatment, and you continue to take your treatment to keep you feeling well, and to prevent or reduce the risk of complications, because you are at a higher risk of developing diabetes than, you know, your Caucasian counterpart.

- (14) And now, returning to all patients. In the time that you've been specialising - twelve years, since 1996 - what would you say have been the main changes in diabetes care?

Okay, I think there's been a big push for self-management, 'cause I think, previous to that, it was very much - and this is the way the patient saw it - more of the domain of the healthcare professionals to tell them what they needed to do. I mean, when I first started, we used to do a lot of group education or one-to-one education sessions, and the patients would stay... not stay in, but they would come to us every day, so they'd be there for three days. So, basically, they'd come the first day: you'd teach them how to inject their insulin, you'd talk about their management of their treatment. They'd stay in and they'd have a meal, and we'd look at their carbohydrate, and then they'd inject on the evening. And then they'd come back the following day, so... And that would be repeated, and they'd have various educational interventions throughout that period of time. And now what we do - and that has changed in respect - is that they only come in... the majority of the patients will only come in for a couple of hours, even if they are new to injecting. And they would inject themselves - they'd come in and they'd inject themselves - and then we would sort of keep in contact with them via telephone, or they'd come in for consultations - what we call nurse reviews or nurse appointments - as and when they need to. So, in that respect, that structure has changed. Also, there has been... I mean, we have the advent of the NSF - the National Service Framework - where we've had particular standards put in place. And the standards that have an impact on us, really, would be inpatient education, and also inpatient care, and also outpatient care. So, we've been looking at structuring... although we've been structuring the education for patients, I think everywhere, it isn't universal. So, UK wide, you would go somewhere... you'd go down south, go to a London hospital, and it, although the content would be the same, it would be delivered slightly differently. You'd go up to Scotland, or whatever, it would be different. So, what they're saying is that we need to try and structure the education packages. And so they have been... a lot of education packages that have come out, such as DAFNE - which is Dose Adjustment for Normal Eating - and that's a structured education, five-day education package, for patients who have Type 1 diabetes, teaching them how to manage their diabetes by looking at the carbohydrate content of their food, and adjusting their insulin appropriately, which is based on a educational package from Düsseldorf in Germany, so... And most people would actually say that we've actually been doing this for a long time. The principles are the same, we've just re-jigged it, and sort of delivering it in a different way.

(15) Also, the principles for and the delivery of education for people for Type 2 diabetes, as well. And you'll come across... there's lots of acronyms: there's BERTIE and there's DESMOND, so that's for Type 2 diabetes, so ongoing teaching for people with Type 2 diabetes also. And depending on where you go in the country, there are different sort of educational packages - structured educational packages - which are actually been identified as being approved by the National Institute of Clinical Excellence, which is something... which is a body that actually looks at different forms of treatments, and decides whether or not they're cost effective or beneficial. Because, obviously, we know that there's lots of things out there, there's lots of medicines, there's lots of educational packages and things, but they have to be proven to work and to be cost effective, and this is what this particular body looks at. And they've approved things, such as the DAFNE, and such as the DESMOND, and other educational packages, which have developed out there. And, obviously, they want to ensure that the patients that are receiving this education, that it works, and it's all been sort of assured and approved and assessed, really. So, I've been involved, and I am DAFNE trained. I had to undergo the education for that, and I was assessed delivering it. And we're very lucky, in a sense, that within the Trust that I work with now, we've actually delivered nine of these courses, and hope to continue to deliver them every two months, and hoping to offer this course to patients with Type 1 diabetes.

(16) And in your experience, how successful is the DAFNE programme?

At the moment, there's mixed results, really, because we tend to use the marker of HbA1c as a gold standard, so Haemoglobin A1c. So, basically, this is a measurement of sort of the amount of glucose that's been in that particular patient's bloodstream over a period of time, and it's a bit of an assessment of how well they've been controlled. At the moment, the results aren't... the HbA1c results aren't, perhaps, as good as we anticipated, although the majority of patients' feedback is that it's given them a new lease of life. It's normalising the way that they live, they're able to eat and drink what everybody else does, and that they're in more control. So, it's early days, and we've only been doing it for just over a year, now, so we'll revisit it and see whether or not there are other things that we need to put in there to improve that. I enjoy the week, and the majority of the patients enjoy the week. And one of the things they talk about is actually knowing that they're not alone, and they're actually able to talk, for the first time, about their condition to somebody else that actually understands, so I think that's a very positive thing. We obviously need to work on the overall control, because, as we know, that poorly controlled diabetes does lead to, you know, increased risk of complications. So, there is a positive aspect of it for their well-being and quality of life, and they are aware that we're also looking at the other markers as well, the important ones also - not to say that quality of life isn't important, because it is. So, as far as education is concerned, we are moving forward, although a lot of people would say we're just reinventing the wheel, as it is, or just portraying it in a different way, because, when I speak

to other people, they do actually say to me “well, we were doing this years ago, but I suppose this is you giving us a little bit more sort of...” - what’s the word I’m looking for - more self management... more control, putting the control back into their hands, really.

- (17) There are other things, other changes I’ve noticed, also, is obviously we had syringes. Patients used to... I mean, they regale me - I wasn’t in diabetes when they talked about the glass syringes, and boiling them, and sharpening needles. And I’ve met that a lot, recently, delivering the DAFNE course, because they talked about having to sharpen needles, and scared of using their needles. And now, they’ve actually got the pen devices, which are much better. I mean, I can remember when they used to press it, and each time they pressed it, it was sort of one unit, so they had to keep counting. But that was better than syringes, they all said. And now we’ve got a variety of pen devices that we can use for different patients and different needs, which is great. And also, new insulins, because we started off with our soluble insulins and animal insulins, and now we’ve got what we call the new generation insulins: analogues, quick acting and long acting. So, they’ve got a better and a bigger variety of choices of treatments that they can use to suit their varying lifestyles. Also, on the horizon - and it has been launched - was inhaled insulins, and I’ve had a bit to do with that, as well. I’ve had some experience with that, being part of a centre that’s been using them, and seeing the successes with that. Unfortunately, the current inhaled insulin has been withdrawn, but we’ll see; there’s still a lot in the pipeline. There’s also an interest of mine is insulin pumps, or what we call continuous subcutaneous insulin infusions, and since NICE, back in... it’s got to have been back in 1995, decided that it was a good treatment to use for patients with Type 1 diabetes, so we’re using that. We have what we call a pump clinic, and we have at least thirty patients, now, using continuous subcutaneous insulin infusions, and majority of them very successful. And it’s sort of changed their lives as well, and it’s allowed them to make the insulin to work better for them, because it delivers smaller... it’s a delivery device that actually you program it, and it will deliver the amount of insulin that you need at a certain time. It’s hard work for the individual patient, but those that are motivated and switched on, it works well. And I feel quite proud to be involved in that innovation, also. And there are newer treatments, and because we’re a university hospital and we’re a teaching hospital, we also do research. We have a research centre, so we’re looking at the new therapies that are actually coming on the market, and we are actually quite lucky, in a sense, that we’re able to offer our patients those treatments.

- (18) We’ve talked mainly about changes for patients with Type 1 diabetes. Have there been many changes, in the last twelve years, for patients who are on tablets?

Well, the majority of the education is very similar to those who have Type 1

diabetes, so a lot of our patients are being seen under the care of their general practitioner, unless they have any specialist problems that will mean we need to monitor them very closely. But a lot of our Type 2 patients, who I see, are those that go from oral agents or tablets to insulin, and the education that we give them, as we said, is very similar to that of those who've got Type 1 diabetes who go onto insulin. So, those... their education sessions have changed quite a lot, also, within our centre. And the tendency is now is just to bring them in for a couple of hours, in groups, for education. Obviously, if they're unsuitable, we will do one-to-ones, and we will see them as often as that indicates, but normally they will have sort of a set two hours, two or three hours, initially, when they're seen by ourselves and a dietitian. And we try to make that a joint session, because people are busy, they have working lives, they have to take time off work. And what we do is we bring them back two weeks later for another couple of hours education, and revise what they already know, and assess what they have learnt. And we've cut that time quite substantially, because then, the other service that - on the back of that - what's actually picked up is the fact that we have a telephone advice line. So, if patients have problems in between, then they can, in fact, ring us up and talk through, and tell us what they would like to do, and then we would advise them whether or not they're right or not. That's giving them ownership, that's putting the management back into their hands, because, as with any chronic illness, you want them to be able to manage it themselves, and then just access our specialist care as and when they actually need it. Also, we used to do sort of education sessions, and we used to - quite wrongly or rightly - used to call them Type 2 education sessions. And we used to bring people in for an hour or two to talk about the key management of subjects due to their diabetes, and skills that they actually need. But we now, the majority of those patients actually go out into what we call primary care, and they access structured education sessions, mainly the DESMOND, and others will access things like the Expert Patient, depending on where and what they actually have within their locality. And several of our specialist nurses actually input into those sessions, so that we keep a... basically keep a partnership between primary care and the hospital services, specialist services, because then, obviously, they dip in and dip out, as and when they need to, or refer in as and when they need our services.

- (19) We also used to - and this is a thing we're thinking of doing - is giving the patients - not only Type 1, but Type 2 - a focus, so they can come in and have... you know, talk to other people who've got diabetes, and not wait until they're acutely unwell. And also, a patient of mine has actually set up a website, so that they can talk in their chat rooms together, and talk to other people who've got, you know, the condition, as we said. Because one of the things is, they feel, although they sit in a waiting room with somebody who's got diabetes, doesn't necessarily mean they want to talk to them, and they don't. So, they network via this, and it's this thing about being quite anonymous, when they can talk to each other in their chat room on the internet, which I think is quite good, and that's a recent

development too. And as for - as we said, it sounds as if we just talk about people with Type 1 diabetes - but as I was talking earlier with the new therapies, we have been in a position where - and I don't know whether anybody's heard of it - and you probably would have heard of an injection called Byetta, which patients can have, that helps them to utilise their own insulin better. And that is predominantly... that is a treatment for patients with Type 2 diabetes. And we have clinics... we're setting up specialist clinics to start patients off on that, and obviously to assess the effectiveness of that. And there's also a oral medication called Sitigliptin, so that's another new treatment that we're sort of involved with in assessing. And also, we'll be undertaking research, hopefully in the near future, to see how effective and the best ways in which to give it, et cetera, just to ensure that our patients have the best possible treatments available.

You've mentioned, several times, patients having to spend less time in the hospital, even ones who are going onto insulin for the first time, and you've given a couple of reasons. One is that patients are busy and are glad to spend less time. Another is that it's empowering them. Another could be, of course, that there are many more people with diabetes, and so you haven't got the time or you haven't got the money. So, what are the reactions of the patients? Do they complain they're not getting enough time, or are they happy with the way things are going?

I think it's mixed, really; it depends on the individual patient. A lot of them... some patients even find it difficult to come for the couple of hours every couple of weeks, so you have to negotiate and see what's best. Although, I did meet a patient, several weeks ago, who remembered when he initially started insulin, and he was in for the three days. And then we changed his treatment over, and he went "ooh, gosh, this is different". And he was talking to somebody else, and he was saying "oh, gosh, and we used to have to be here for three days, and it's much better now that we don't have to come in every day, and we're only here for a couple of hours. And they're on the end of the telephone if we need them, and we can ring them and make an appointment when necessary". 'Cause it's, I think, it is very much about giving them ownership. I think if we, in a sense, just put lots of input - which is right, they need the input - but if we take over - which is what I think, personally, may have happened many years ago. We used to do a lot for them, as opposed to allow them to do it themselves - I think it's then harder for the individual patient to actually take it on board and do it themselves, because "well, you used to do it for me, didn't you? You used to make the changes for me". So, therefore, if you start from the very beginning, for those patients that are capable of actually self-managing, and start as you mean to go on, in a sense, then they realise that that's the expectation and they just get on with it. And the majority of them will take that on board, and they're quite happy to do that.

(20) Can you talk about how you, as a nursing specialist, relate to other

healthcare professionals?

Well, we work as a multi - hopefully - as a multidisciplinary team. And although I'm based in the outpatients, I do go onto the wards and do inpatient care, although we have a specialist nurse that... she has a keen interest in that, and she's developing that part of the service. I tend to work within... in the outpatient arena, and the majority of our patients are referred either from hospital or from their general practitioners, because we, I suppose, we're seen, within the hospital, as specialists within diabetes, so we look at the patients who have more complex problems. Obviously, we talk about looking after patients who've got sort of Type 1 diabetes, and the majority of them stay with us throughout their care, and then uncomplicated Type 2 diabetics who generally come to annual review clinic. And if they're stable, the tendency is that we refer them back to the general practitioner, and he cares for them, and they're seen in the general practitioner clinics. Although, we do have, also, clinics out in the community, intermediary clinics, which actually have a GP with a special interest in diabetes, but also has consultant from the hospital, so they're working in partnership there, so they can actually share their expertise. Also, obviously, clinics such as the maternity clinics, the antenatal clinic, they're run in partnership with the women's hospital, within our Trust, and I suspect very similar in different diabetes centres across the country. Renal diabetes clinics, also. We also have what we call erectile dysfunction clinics, so patients who have diabetes and need specialist interventions there. Also, we have GPs who actually work within our annual review clinics, as well, so they actually have their specialist support from the consultant within that clinic. But I think what's envisaged is that, eventually, annual review clinics probably won't exist within the hospital setting. They'll actually be run out there in the primary care clinics, and will be replaced by more specialist clinics within the hospital. Although, it's hard, I think... I think what's going to happen is that we will be working very closely, because as we know that... I think we all know that the primary care trusts will actually hold the purse strings in chronic disease management, and what we may see is that they just access or pay for our services, or want to, under an umbrella, where we actually work very closely with them.

(21) And can you describe a typical week in your working life now, in 2008?

I mean, I currently work part-time, so I only work three days a week. So, my typical week, really: at the moment I do a research day, where I look at specific patient groups, looking to see who I can recruit for specific studies, see if they meet criteria, you know, send out letters or ring patients up, take blood samples, et cetera, fill out questionnaires, et cetera. And that would be the first day. And then the following day is a bit of a mixture, really, because I have input in my own sort of, what we call, nurse-led clinics, so I see individual patients and assess their need to change treatments, make telephone calls, and, of late - and that's quite interesting - since we've got computers and things, because there are a lot of phone calls come through and patients can't get through on telephone, I'll occasionally get emails through from patients asking what do they need to do



next. And we have quite a lot of conversations via the internet, giving them input and advice regarding treatment, where to go next, et cetera, holidays, you know: what do they do when they go on holiday, do they have to change their treatment, so? And then, obviously, accessing and supporting clinics run within the department. May also do a slot delivering education sessions to the multidisciplinary team, so it could be to student nurses, it could be trained nurses, it could be student doctors, it could be trained doctors, GPs, practice nurses, et cetera. And then, running a joint clinic, also, because I am involved in what we call the pump clinic, so I was talking about the continuous subcutaneous insulin infusion clinic. Also involved in preparation for DAFNE, so assessing patients for the next DAFNE course, and looking at the waiting list, receiving referrals down from clinic, discussing with the doctors, you know, plans of action, management of certain patients. Also, sitting in multidisciplinary team meetings, as we said, looking at cases, discussing cases, looking at new treatments, protocols and guidelines that need to be developed within the department. And, as I said, being that specialist adviser within different clinics. Telephone consultations, also, with GPs, practice nurses, and obviously with the patients themselves. Most of the time, I have a structured clinics, really, just seeing individual patients, or their carers, and discussing what they need to do next, or just telling them that they're doing fine, and discharging them, really. So, that, really, is my typical week, and also, as I said, attending conferences as well, networking meetings. I'm going to one next week!

(22) Do you feel you spend enough time with patients?

Yes, I mean, we have more time, typically, in a consultation, than the doctors and consultants would have. I generally set aside half an hour per patient, in order to gain a good history, to deliver what education I need, to advise on treatment regimes. If, you know, obviously we finish early, great, it gives me ample opportunity to write up notes, send out letters, et cetera. But generally, half an hour is a good time to be able to give a thorough consultation with the patients. For example, if I'm answering a telephone consultation, and we generally time those, those could be as little as five minutes, but as long as forty minutes; there's no set time for that, really. But generally, my set clinics, I will give each individual half an hour. And if it's a new patient, somebody you've not seen, I will actually give it an hour, so that I can obviously get to know that individual properly, and so that I can get a thorough assessment of their needs, really. And usually, once I've seen them, I know how much time I need, and then I will book as and when, as necessary, really.

Is that surprising that you're able to spend as much as half an hour, or occasionally an hour, when you've got so many patients with diabetes?

I think we're very lucky in respect of our particular department, because we have several diabetes specialist nurses - nine whole time equivalents, really - so we're able to spread our time effectively, and we do see the number of patients. And we looked, actually, every month we look at how many patients we actually see, and we see at least a hundred-plus patients in that particular time, sometimes more.

But, as we said, we get to know our patients very well, and it's not normally just a one-off appointment that we actually see them. And the more we see them, the less time we need to spend with them, really, so more patients. . . we see more patients in the long run.

- (23) And finally, would you like to compare what life was like, for both you and patients, in 1996, with what it's like now?

Yeah, I think, over the last twelve years, things have definitely changed, and when we've seen new technologies, new insulin treatments, just the fact that syringes and pen needles and things are on prescription, reducing the cost for the patients to be able to manage their condition. There've been more, I think, more time - although lots of people may say, oh well, we don't have enough time to spend with their patients - but we've developed different techniques and strategies to actually deliver education. We've moved from sort of one-to-one sessions with the majority, and now it's more group work, more adult, sort of, education principles applied. And I think, although we have developed quite a lot in 1996, with the fact that one of the first diabetes specialist nurses actually hailed from Birmingham, so we did have a good start, but, in fact, I've seen that our specialities have grown, and we have a lot more sort of specialities diabetes clinics, and diabetes nurses with a special interest in certain subjects, that I feel as if patients are getting more sort of value for money and more expertise. And there will be more emphasis on developing our profession, and delivering a better standard of care for our patients. And, as we speak now, there are more innovations within diabetes, and hopefully that should be for the best for our patients. So, we've changed the way in which we work, hopefully for the best care for the patient.

But, as one-to-one is replaced by group education, do people get a chance to air their particular individual worries?

Yes, because we have to assess each patient individually, and if we feel as if they. . . although the common theme is that we do groups, because if we do groups we can see more patients, however that doesn't mean that everybody is suited to group education. So, we still will assess each individual, and see which way in which they need to be taught, which is more beneficial for them. So, we still have, or we still will have individual education for patients.

- (24) Now, you've listened through to what you've said so far, and there are a few corrections and additions you'd like to make, so go ahead.

Yes, I found it very interesting as I listened to it. I totally missed out that my father was actually a hospital porter for roughly around ten, fifteen years, after he left the power stations. He was retired due to ill health, in that capacity, and had to retrain, and it was funny, really, that he actually ended up working in the local hospital. And he really enjoyed that, because I think he's a bit like myself, he's a very personable person, and he went round and made lots of friends, and spoke to the patients as he wheeled them through the hallways. And I'm wondering whether or not that, and my mother's profession, made me sort of, as

I said before, drift into it. I probably subconsciously felt that was something I could do as well. The other thing that I was talking about, really, was technology in diabetes, and the different changes which would have had an impact on the patients. I mean, I remember, back in March 2000, they had needles free - pen needles free - and these are some of the things that I think we take for granted, you know, something that makes their life a little easier, makes their ability to inject their... administer their insulin easier via the pen devices. 'Cause even pen devices themselves, they were virtually new when I came into nursing. They had a few pens, and as time went on, they developed quite well, you know, from your one unit or two units injecting each time you pressed the button down, to pens that were disposable, and pens that dialled up half a unit, et cetera. And I also remembered, also, that disposable pens weren't on prescription either, and it's down to Diabetes UK, and their lobbying the government, that they were then free for patients to use. So, if we look back in history, on diabetes, as well, realising from... because I spoke to some patients on the DAFNE course, and they were telling me they used to have glass syringes, and really thick wide-bore needles. And they only gave them one at the very beginning of their diagnosis, and when the needles became blunt, they actually filed them so that they didn't hurt when they injected them. And they boiled them on the top of the stove, or put them in methylated spirits to sterilise them. So, when I look back and see how easy my job's been made by the new technologies... And I'll just briefly talk about the fact that, you know, we had... we went from boiling up their urine or putting chemicals into their urine to get a sugar result, to the fact that we've got blood testing devices that only take very small, like three microlitres of blood, and take five seconds to give them a result, there and then, so they can actually make changes straight away. That has made my job a lot easier.

- (25) I suppose that, also, being a diabetes nurse specialist in diabetes, or clinical nurse specialist in diabetes, I look back when I was training, or just before I was training, I had a O Level, O Level equivalent education coming into diabetes. And I was aware, a lot, of other people had A Levels and things when they actually attended also. And most of my experience and my qualifications is through on-the-job experience, and also diabetes-specific educational training. Back in the late 1990s, when I was reading through the journals, they actually spoke about making diabetes a profession in its own right, and in that way they had to structure it a little bit more. And they talked about degrees, which is what they're doing now, so there's a degree level of training, and also a Master's degree training, going to uni and doing their Master's. And I suppose that's something that most diabetes specialist nurses should be looking to have, to enable them to deliver the role that they are doing, and that will identify them as a profession in their own right. And the other thing I mentioned, really, was about Afro-Caribbean nurses in diabetes specialism. Well, there are lots. Within Birmingham I can see them, because, as I stated before, it probably is due to the population that we have. But back in my mother's time, and I'm discussing with her, I think most people came into nursing and did

the general day to day job within the ward areas, perhaps doing a bit of community nursing, and things, because there weren't that, in a way, a structured professionalism - there wasn't like specialist nurses in diabetes, then. And that's probably why you don't see them, or there are very few of them, if you want to talk to them. But that is developing. And I think people within different races, such as Afro-Caribbean, Asian, et cetera, do have a special insight into how their particular patients will actually deal with circumstances, managing their illnesses, and it would be good if we start to attract people from those particular groups.

And one more point you just thought of.

And one more point, as we're talking about developing... the development of clinical nurse specialists. Of late, in recent years, we have developed the profession in such a way that we now have consultant nurses, and this has definitely strengthened our profession, and allowing us to develop further.

So, how do you feel about the fact that you came into the profession with O Levels, and people now are coming into the profession with degrees?

I do feel that I need to perhaps undertake a degree or that level of education, and I do put myself under pressure to actually develop in that way, because I do... you know, I have got a lot of experience, and I've been in diabetes nursing for twelve years, and I like to think that I do operate at a good standard. However, there are, I suppose, some things that you need to learn through academia, and, in the future, I have plans to go and improve my qualifications in that area, because I think that in order for it to be a profession, we do need to develop in that way. But the other thing you have to understand is that there are a lot of people out there, like myself, who came in with my standard of education, and have a huge wealth of experience in diabetes nursing, and I don't think that should be ignored.