56. Shanaz

(1) Tell me about your background.

I can remember growing up in Balsall Heath. My Dad was a factory worker for twenty two years, for Lucas on Formans Road, which is now closed down. All I can remember about Dad is, basically, he did nights, which was a good, I think, six nights a week. And we only ever saw him when he used to get up in the afternoon, and then he was back out again by seven o'clock. So, we didn't see a lot of Dad. And Mum: Mum was your typical stereotyped Asian woman, of that time. She was uneducated. She was brought over by Dad. She was illiterate in her own language, and in English. And basically, she came from a very poor background, herself. And she came over - Dad brought her over round about, sort of, 1950. He came over round about 1948 - and she basically just looked after the kids, looked after the house, looked after his family and him. And that was her role, and Dad went out to work.

How many brothers and sisters?

There's two brothers, I've got, that are... one younger than me and one older than me. And I've got two sisters that are a lot older than me.

When was your father diagnosed with diabetes?

He was thirty seven when he was diagnosed with diabetes. He told me that he was suffering very badly with his asthma, and it was round about that time, when he was about thirty seven, that they diagnosed the diabetes as well.

What year was he born?

He was born in 1924 (in fact 1923), and he said he was thirty seven when the diabetes, they diagnosed it.

And, obviously, he had diabetes... your Dad already had diabetes when you were born. What are your earliest memories of it?

My earliest memories of Dad having diabetes was Mum making him food separately. He used to have vegetables with curried meat, and she used to save the curried meat for him, and put it with a plate, so that when he got up, he had that. And we basically just had the curry, or whatever else Mum had made. But she used to make a special effort to make sure he had his vegetables, his potatoes, and his curried meat, and he had that every day.

What kinds of vegetables did he have?

A wide range; I was quite surprised. Swede, green banana, potatoes, carrots, sprouts, broccoli. Anything that was going, basically. I'm actually quite surprised, now I think about it.

(2) But not typical Asian vegetables, then?

No. Around about... I mean, because Dad came over in 1948, they were probably the first collar workers that actually came over. And at that time, in this country,

I don't think there was an abundance of Asian vegetables or ethnic foods, as such, so Mum had to basically cook what was available. And that's what they were teaching you in the diabetes centres: this is what you have, so Mum had to stick to that.

This would have been, say, the very early 1960s, when there were a fair number of Asian people in Birmingham. But is your impression, then, that the hospital didn't provide any Asian diet sheets?

Absolutely not. I think Asian diet sheets, really, have only sort of started to excel in the last sort of ten years. But, prior to that, absolutely nil. Mum was taught... was told by Dad, basically, what he was expected to eat, and she just went along with it.

Was that hard for her?

I don't know - Mum passed away three years ago. But I think it became just part of her routine, and it was just, it's what the housewife does, so she did it. She did as she was told. I now know that... I mean, Mum was quite unique, in the sense - Mum and Dad - in the sense that Dad was compliant with his diet, and that Mum was compliant in the fact that she actually did what Dad told her. And he had this well balanced diet every day. But when I look back, now, a lot of ethnic minority groups, particularly Asian people, it's very unusual for them to have boiled food, because they basically stick to their ethnic foods, such as curry, chapatti, rice. And if they were to do that, people probably who didn't comply in those times were the people that ended up with the complications. And this is where Dad is unusual, because he's coped with diet and tablets for so long, and he's done really well. And he hasn't ended up with any complications, as a result of, probably, him fully complying with diet and taking the medication. But, even now, the ethnic minorities, the Asian people that I deal with, they are so non-compliant when it comes to diet, it really did make Mum and Dad very unusual.

And did he ever have to go onto insulin?

Yeah, Dad's been on insulin, now, for a few years. He's just recently, I think within the... I think it's the last five years he's been on insulin - insulin injections - once a day, which my brother is managing for him.

(3) Can you... have you had any impression of what attitude your family and friends have had towards diabetes?

It's just the run-of-the-mill. And I think that's because of our experience with diabetes, in the sense that, if you lead a life, whereby you do comply with treatment and you do comply with your diet to some extent, that you can lead a fairly healthy lifestyle. And I think that's just because of what we've seen from Dad. We've not seen him get any complications and that.

Do you think he found it hard to eat English food?

I haven't asked him that question. But he seemed to enjoy his food, and I think that was just because Mum used to put a bit of curried meat on the side, so it used to balance it out. And he never used to feel ill; he used to feel well. So, to him, it was probably okay.

Tell me about the other members of your family who've had diabetes.

I've got an older sister who's got diabetes; she had it about four years ago. And I have another sister, who's just slightly younger than her - two years younger - she had her diabetes diagnosed about two years ago.

So, tell me about your sisters' experience of diabetes.

My older sister, that was diagnosed about three to four years ago, she was complaining of symptoms of just feeling very tired, and she was feeling thirsty, getting up in the middle of the night; typical symptoms. And because I was a Diabetes Specialist Nurse, the first thing I said to her was "well, have you had your blood sugars checked?", and she said "no". So, I had a meter at home, and I did a check on her, and it was slightly elevated. So, I asked her to go back to her GP and have a test done, which she did, which confirmed the diagnosis. And, basically, she started on diet control, and she's been on... just recently been put onto Metformin. Actually, she's been on it for about a year or so, and she's doing really well. She's again... she has Asian foods, but they cook in a healthy way. And she's managing to keep her sugars under control, because she monitors her sugars. And they keep in close contact with me, so that if they're not doing anything right, I sort of like whip 'em into the right way of doing things.

Was she given advice on an Asian diet for diabetes?

All the advice that she received was from myself. She's been managed by her GP, and I gave her all the literature, which was in English, 'cause my sister can read English. And, basically, nowadays, they do modify the diet to incorporate the Asian diet. So, you can modify it so that you're having the right portion of fruit, veg, according to the amount of carbohydrate that you're having.

So, tell me what a typical day's diet would be for her.

She gets up, and she has, basically, a cereal, or some... a boiled egg, or toast. And then, basically, she has sort of some fruit or some yogurt, sort of half way through the day, to keep her going. And then, at lunchtime - she's not a very big eater - she has a sandwich, or just a little slice of bread with a bit of curry left over from the night before. But the right amount, so the portions are right. And then I think she has sort of cup of tea in the afternoon, and then she eats about six o'clock. About six, seven o'clock, she has chapatti, or rice and a curry, and just a hot drink before she goes to bed.

(4) And how does she feel, most of the time?

She feels okay. I mean, the diabetes is not giving her much of a problem, because her blood sugars are controlled. And if... Her GP keeps a track of her. Every

sort of three to four months, they do a blood test to see that everything's okay, and if something's up, her GP does something about it. She also tells me - 'cause I like to know what's going on with her - and if I'm not happy then I mention to her that she should go back and see her GP.

You're quite a close-knit family, then?

Definitely. We fully support each other. We're very close, and we stick together.

So, tell me about your other sister's experience.

My other sister's experience: Basically, they, as a family, ate very unhealthily. They had a lot of fat in their diet - high fat, high salt diet - and every time I used to go down, I used to have a moan. But, as with any family with a health professional in it, they don't listen to them until something happens, and then it's "what do we do now?". So, they did have a very unhealthy lifestyle, no exercise. But now her own kids have grown up - one of them's a doctor, one of them's a dentist, training to be, anyway - and obviously the advice that they're bringing in is being adhered to. But I really do feel it is because the fact that she's now diabetic herself that she's sticking to the advice.

What kind of things did they eat before?

I think it was the amount of fat. They were eating a lot of red meats. They were, because the husband is - obviously we come from an Asian background - and it's... they need meat in the house; it's prosperous. Red meat, they needed it at least three to four times a week. There's always meat cooked every day, whether it's chicken or red meat. So, that was one of the aspects that I told her that they really did need to cut down on. And the amount of fat. I mean, I went to her house, the one day, and she was frying an egg. And you could... it was floating in the pan! And I just... I was absolutely disgusted that my sister was frying an egg - and she's educated; it's not that she's not educated. She's a teacher herself, and she's got an honours degree - and yet she was frying an egg in so much fat. And I told her off. And I think the next time I went, there was about half the amount, but even then, it was just not right.

So, what were the major changes she made?

Major changes: Basically they now oven-grill and non-stick pans. You hardly see any fat in the house, now. And the amount of salt - they don't add extra salt to their food. They've bought a running machine. They've all lost weight - it's not just her - and they're basically, they're motivating each other. And they are; they're doing really well. I'm really pleased with their progress, the lot of them.

(5) How have they managed to find time for exercise?

My older sister is sixty one now, so... I mean, she did have to retire about a year earlier than she did intend to, due to ill health, 'cause she's got a chronic back problem, and she's under the pain clinic for that. So, she is not able to do exercise, as such. But, having said that, she's a real goer; she just won't give up. She gets up, she does as much as she can. She's on very, very strong pain killers.

So, she is on the move, most of the day, in her house, a little - maybe a few hundred yards outside the house, maybe to the local shop, or my brother takes her out. So, she doesn't stop. She has been swimming, 'cause the hospital have told her that swimming might be the better option for her. So, she's been twice now, and that's going to try and help her build some of the muscles in her back. And she's said she enjoyed that - she's been with the grandchildren - so I have a feeling that she's going to start doing a bit more of that. But, as far as her weight goes, her weight's okay, so it's not that she needs to lose any weight, but it's just to try and keep healthy. So, that's what the family are trying to do for her, and she's doing for herself. And my other sister, like I said, I mean, she's the one that's made the major changes. They've bought a running machine; they've stuck it in their front room. She's started yoga; she's also started salsa classes. She's actually motivated me to lose weight this year. So, she's made some major changes, as have the whole family.

And would this change of lifestyle seem odd to their friends, neighbours, family?

I think, because they are so busy - career-wise - I think people understand that we are the way we are. And, although they... I think Asian people, in general, are taking just more of an interest in health matters, such as exercise, because of the weight issue. And looking good is so important nowadays, so people are taking more interest in the way they look. So, I don't think... no, I don't think they get an y kind of negative views, or... from relatives. It's actually, probably, positive, more than anything.

Was there any problem for your sister who swims in finding suitable swimming sessions?

No, because my family, in general, are quite broad-minded, in the sense that we don't mind going to a swimming pool if there are men, or... men and women mixed. Having said that, they do have women's sessions here, and I know she has been to one or two of them, so it hasn't been a problem at all.

How does your father and your sisters, how do they manage during Ramadan?

I mean, the Qur'an does exempt people from fasting if they are unable to - if you're very old and frail, and if you have chronic disease which doesn't allow you to do it - so they are exempt. But, as many people do, nowadays, they do want to still fast; so, with the right advice, there's no reason why they can't. As far as my older sister goes, she is on a lot of painkillers. She did try fasting last year, but she was very ill with it, so she didn't keep all of them, but she did have a go. My Dad doesn't fast; he's too old and frail. And my other sister - the one in Leicester, the one that's not the oldest one, but the other one - she doesn't fast, because she does really feel ill if she does, so she doesn't fast at all.

How have you, yourself, been affected by having three family members with diabetes?

It's broadened my knowledge. It's... just my insight into how different people deal with it, and how cultural influences can actually change the way that you

deal with it, and how you come out of it. When I look at my Dad, and how well he's done, it just shows you that a healthy lifestyle can contribute to you not having complications, and I'm hoping that that's the way that my sisters are gonna go. But, when I look at people that don't comply with treatment, and don't comply with their diet, you can see how they do become ill. So, to me, it is a disease that you can manage well, if you want to, and lead a normal, healthy lifestyle, if you wish to.

(6) Now we'll move on from your role as a family member to your role as a health professional. Tell me how you came to work in medicine.

Since I can remember - since I was very small and I had my first medical pretend play kit that my sister got me - I wanted to be in the medical profession. I wanted to be a doctor; that was it. And basically, I went on through school, got my O levels, got my A levels. Unfortunately, the grades that I needed for my A levels, I didn't get those first time round, so I didn't get into medicine first time round. And I did re-take them, but unfortunately I didn't actually get round to going to medical school, and I ended up in nursing, because of family issues at the time. And, basically, I just stuck to nursing, and that was it; and one thing led to another.

So, when would you have first encountered a patient with diabetes, outside your family?

1988, when I was training as a student nurse. We used to see diabetics coming into the medical ward all the time. So, I saw them all the time, basically, while I was just a student nurse.

Where was this?

I trained as a student nurse at Selly Oak Hospital in Birmingham, and we were the first pilot group that actually piloted the Project 2000. We were one of five sites in which we got a diploma and an RGN qualification in one. So, I really enjoyed that.

Were the people you encountered with diabetes coming in for their diabetes or for something else?

Both. They were basically coming onto a ward with complications from diabetes, or maybe uncontrolled diabetes, so it was a combination of both.

What are your memories of that time?

I learnt a lot. I made a lot of friends. I had some very good mentors. You learn what's the best way to do things, and the old style of nursing was the real nursing. The new style of nursing... I think nursing's changed. Nursing isn't what I went into nursing for. I think it's very academic career now, and a lot of the bedside manners, and the things that people actually originally went into nursing for, aren't actually there. So, that is one of the reasons I actually left the wards, because I didn't feel the job satisfaction was there any more.

Can you spell that out a bit more? What were you expecting of nursing?

(7) When I went into nursing, I wanted to care for people. I didn't want to be doing paperwork all the time: plan of care, et cetera, et cetera. I wanted to be actually hands-on, because I'm a very hands-on person. I like talking, communicating to people, and caring for them. But as... three to four years into the career - I think it was when the White Paper came out - nursing changed a lot. And basically, after that, it was becoming more of an academic career, as well as, obviously, the hands-on; but the hands-on was becoming less and less. And the turnover was a lot faster: people were coming and going out quicker. It was very much like a conveyor belt system, and I wasn't as satisfied as I was when I first started nursing.

You mean the turnover of patients rather than of staff?

Yeah, turnover of patients. I mean, an example of this is, we used to nurse people that used to come in with heart attacks, with MIs (myocardial infarctions). And they had to be on this ten day programme, where they had to stay in bed for so many days, they weren't allowed to get out of bed, and then they had to sit out, and then they were allowed to walk one way. And, you know, people didn't come back in; they looked well when they went out. But now it's a case of someone has an MI, they come in, and they're out within five to six days, and, you know, sometimes they are back in again. And it just makes you wonder what's happened to nursing, really. And a lot of the good nurses - the old style nurses - have actually left the NHS, because the job satisfaction just isn't there.

How would that have affected the patients with diabetes; say, when you were training, in the late eighties?

Patients were looked after. I'm not saying they're not looked after now, but... The diabetic patients came on the ward. They had... I can remember the leg ulcer dressings; they were done. I remember the aseptic technique - even that's changed now - and there was no sign of MRSA then. And I remember being assessed for my aseptic technique, and I think my apron touched the handle of the trolley that I was sterilising. And that was it: I failed, just because my apron... But now, it's totally different - it's more a clean technique. And all you hear about is MRSA, so it just does make you wonder that the old techniques, whether they were the better techniques.

Can you spell out, for future generations, what these two techniques are: the aseptic and the clean technique?

Aseptic technique means your hands do not touch that trolley, and that everything is sterile on that trolley. And the only way to, for example, open packets on that sterile trolley is to get forceps to open the packets. And literally, you did not touch what you are using. It's with a sterile forceps that you do everything, and that you clean the trolley. The clean technique is slightly different. You sterilise your trolley, and then you are able to touch the trolley, because you can use the hand gels, and whatever's available. Having said that, the clean

technique is there, and the aseptic technique is still there. But it's more so the clean technique that they use for things like leg dressings, and stuff like that, now.

(8) You trained from 1987 to 1991. Were there any Diabetes Specialist Nurses around during your training?

There was one, that I remember, that used to come up to the ward when patients went onto insulin. And she used to come up and go through everything with them. So, there was actually one. And I remember she used to go on the bus to people's houses, as well, to teach them. That's my memory of the first Diabetes Specialist Nurse, and I think she probably was one of the first Diabetes Specialist Nurses in Birmingham.

And what role did she play?

Her role was to educate the patient, and also to show them how to inject their insulin, and possibly to monitor how they got on with it. Probably not as diverse as the role of the DSN now, but her job was to get them started with the injections, and just to make sure that they were getting the right education.

Can you remember what would have been taught about diet, at that stage?

I didn't... I think it was just the basics, but I really don't... I never sat in on one of these sessions, so I can't really compare.

What did you do after you'd completed your training?

I went on to work as a staff nurse on an acute medical ward, which I thoroughly enjoyed. It was an adult male ward, and I really had a really good learning experience. I had a very good sister on the ward, and she was very much hands-on as well. And I learnt a lot of my practical skills on that ward; the first ward.

Any memories of diabetes?

No, just the usual. People coming in, having their blood sugars tested every hour, every two hours and every four hours; insulin pumps. So, just the same things as what happen now.

If people came in with an acute condition though, that would affect their diabetes?

Yeah, they were put onto insulin pumps and glucose drips - whatever they needed, really, medically - and their blood sugars were closely monitored. That's all I can remember.

(9) What did you do after being a staff nurse?

After being a staff nurse, as I mentioned, job satisfaction wasn't as much as it was when I first started the post, because there were a lot of changes going on in the NHS. So, I decided to go into the community as a practice nurse. I'd also had my first child around about that time, or was pregnant with my first child,

and I decided that I needed a part-time job that suited the hours of me being a parent. I worked a short time at a surgery in a very busy inner city practice. It was my first experience of being a practice nurse. And it was very busy, high ethnic minority, and I was responsible for setting up the clinics for diabetes, asthma, et cetera. And I remember, around about that time, something called the banding system had just come out, so GPs were gonna be paid for whatever clinics that they were going to do. And I just played a very big role in setting those up, in conjunction with the GP.

Had there been no diabetes clinic in the practice before?

There weren't designated, I think, clinics or times. It was just... before, it was just a case of they had an appointment list, and you'd slot in all your appointments, and one could be an asthmatic, one could be a diabetic, one could be an hypertensive. But the actual clinics came about, where you'd have, say, a morning session for diabetics, then a morning session, say, for asthmatics. So, it did change round about that time. And that was purely because of the way that GPs were going to be paid.

And what did you do to set up a clinic?

It was a steep learning curve, because the GPs, I don't think, knew what to do, at the time, either. It was a case of let's see how we do things. So, basically, I started networking, getting reps in for the different disease processes to see what drugs were available. And asking them, really, if they were helping practices to set up clinics. And a lot of them actually did, because, obviously, they wanted you to use their products, at the time. They had the leaflets, so they'd come in and stock you up, and go over certain things, as to what was the best way of doing things. So, I did have a lot of help from outside agencies, from drug companies. And, obviously, other health professionals: going in and sitting in on other clinics that people were doing, and seeing how they were doing them.

This was in the mid 1990s, at least twelve years ago. Can you remember what kinds of patients you were seeing with diabetes?

The surgery that I worked in had a high ethnic minority population, mainly Asian, so the patients that I were seeing were mainly Type 2 diabetics. And I don't think I saw any Type 1s in the practice that I was in, at the time; they were all Type 2. And the main... one of my main roles was to actually screen everybody that came in, to see if they were diabetic, because we had to set up a register. That was one of the requirements, at that time. So, everybody had the health screen, and everybody had their blood sugars checked. And we used to pick up quite a few diabetics, just by urine testing or blood testing, at that time.

(10) Could the practice cope with that number of people with diabetes?

At the time, yes, because the WHO criteria - the World Health Organisation criteria - was a lot higher. Whereas now, the targets have all changed, and diagnostic... the diagnosis of diabetes, and the way it's done, has changed, because the WHO criteria has come down. And also, there are other things that

people are looking for - at fasting levels now, so people are being picked up more, now. And at that time - I think purely because of that reason - surgeries were able to. And also, there weren't as many people being diagnosed, at that time.

When you say they were being picked up, do you mean that people were beginning to be labelled as diabetics, who wouldn't have been labelled as diabetic before?

Yeah. And also, nowadays, people are taking more notice of pre-diabetes, as well, so it's... and tests are being done to see if people have got a predisposition to developing diabetes. Where, in those days, really, if you had impaired glucose and you weren't diabetic, it was just like you were borderline diabetic. And people used to refer to you as, also, mild diabetic, if you'd just gone onto diet. But the whole ethos, and the whole process of the way people look at diabetes now, is totally different. It's much more active - proactive - as to how you diagnose, and how you go on to treat and educate patients now, whereas before, I don't think it was as proactive as it is now.

When you were a practice nurse in the mid 1990s, were you doing much education?

Definitely, because I feel that I played a... I felt that I played a role in getting the message across, because I can speak different languages. And there weren't that many health professionals out there that could speak a language and educate patients in the practice nurse, sort of, specialist nurse role. And so, I felt an obligation to get this message out to the people that couldn't speak English, because I felt as though they were missing out.

Did that involve you in, what, translating leaflets?

Yes: translating, interpreting, getting family members in. Because, it's not just a case of speaking the language; it's understanding the cultural aspects of the care as well, and how you're gonna get the message across. And you need someone who knows about different cultural aspects of care, in order to do that. And I felt I had that, with my broad range of experience.

(11) What did you do after being a practice nurse?

After being a practice nurse, I applied for a post that was being advertised for Diabetes Specialist Nurse with a second language; preferably an Asian language. And I really didn't think I was going to get the job, because I didn't have any experience of specialist nursing. So, I really did go for the job for experience. And when I did go, and ended up with a job, I was actually quite gob-smacked, but grateful, because I really do enjoy my job now.

And what was your job?

I was practice nursing on the agency, at the time, and I really wasn't sure which way I was going. I did enjoy asthma, so I thought I was gonna end up as an asthma specialist nurse. But when this post came about, I went for it. And when I ended up getting it, that was it.

So, what were your responsibilities as a Diabetes Specialist Nurse?

My responsibilities, when I went in, was to deal with the Asian patients that were being diagnosed, or weren't complying with treatment. And also, on an educational element, in using my own cultural experience as to the best way to get through to people from Asian backgrounds, to try and tackle the problem of diabetes - Type 2 diabetes - in the Asian community.

Was this just in outpatients?

It was... no, it was in outpatients, it was on the wards, and it was in the community as well; community visits into patients' homes, which all the adult DSNs did. There was three of us, at the time. The other two actually dealt... I'm not saying that they didn't deal with the Asian patients as well, but the majority of my work-load was the Asian patients, with a few white patients, white Caucasian patients. And the other two DSNs dealt with the majority white Caucasian patients. I work in a Birmingham hospital, and my main job role was to see patients on the wards that were referred to us by the wards for education, going onto insulin, people that were having problems with equipment, or with complying with treatment, whose people's... blood sugars were high. And also, educating relatives, as well. Again, same in the outpatients clinic. The consultants, or the doctors, would refer patients to us for the same reasons. And also, in the community setting, we would go into the patients' homes to start them on insulin, educate the people's relatives as well. Because, in the ethnic minority - Asian people, particularly - the extended family used to... do look after the management of the diabetes for their relatives, therefore you do end up educating the patient, as well as the relatives as well. And by going out into the homes, you can also get a clear picture of what outside influences are going to be influencing the patient. And it just gives you a better idea of how you're gonna go about tackling educating the patient, and what best is gonna suit them.

(12) You must have been thinking about why there was such a high incidence of diabetes among Asian people.

It does cross your mind. But I think, because I'm a Specialist Nurse, and I do keep up to date with journals and go to lectures and study days, you know that, just, basically, Asian people are prone to diabetes; four to six times more. So, you just accept it. And you see it, so you just get on with it.

So, no theories on your own part?

The theories are exactly what's being said, basically. Genetically, we are more prone to it. And also, we are more affluent in this country, whereas back home, climate is different, and people tend to do a bit more walking. They tend to burn off, probably, what they're eating there. But what's happened is, with the migration of people coming here and becoming more affluent, they're doing less; less exercise. Diet hasn't changed, therefore they do tend to put on weight. And, as a result, they do tend to have a higher risk of developing diabetes, just because of the genetic way that we're made up. We're actually apple-shaped and not pear-shaped, and because of that, we've got something called central obesity. And because of that, we do tend to be more prone to developing diabetes. I was

a Diabetes Specialist Nurse from 1995 to 2000. And then, one of the consultants approached me, and asked me whether I would be interested in taking up a study, which involved Asian people, very similar to the UK PDS, but to do it with all Asian people from the UK. And, obviously, I was very interested. And then, at that point, we went about starting to set up the UK Asian Diabetes Study. My boss came to me with the study outline, and then it was my job to basically get it up and running, which I did between 2000 and about 2003, for the pilot study. I recruited four hundred patients from Birmingham. And there were two surgeries: one was a control surgery and one was an active surgery. I also, then, had a link worker that helped me with the study, to help educate the patients, and to educate them about the diabetes, and follow them up, do the check-ups, the annual reviews, blood pressure checks, et cetera. So, everything...

(13) But I'll explain what I do on a daily basis. I mean, the pilot study only went on for about three years. When that was complete, we had some very good results from that, which showed that you can improve control in Asian patients, provided there is a healthcare strategy in place to do that. But obviously, for research purposes, we needed to go on to the second phase, which was on a larger scale, to prove it statistically, which I am in post for now. And what we're doing now is, we've got two thousand patients, of which about one thousand eight hundred are Asian, and another two to three hundred, maybe four hundred people are white Caucasian patients as well. So, it's a much larger study. And we are, again, out to prove that we can improve control with diabetes, lipids and hypertension with a good cultural strategy in place to help you do that, which involves the use of link workers, protocols, protected practice nurse time and a Diabetes Specialist Nurse co-ordinator. And, basically, the daily running of it is - from my point of view - is to co-ordinate all services, to make sure that the right care is given to try and bring down the targets for hypertension, lipids, and glucose. My role is also educational, so teaching the GPs, practice nurses how to use the protocols, and how to run the nurse-led clinics. And then, also, for research purposes, to make sure that all the data's collected.

How much time are you able to spend with patients?

I would say about a quarter; about 20%, 25%. And that is purely in my role with working with the practice nurses in the clinics, to show them the best way to do things, and to use the protocols, and what to do with the medication changes. So, it is... I really do enjoy working with the patients, because, like I said, I am a hands-on person. But I only do get about 20 to 25% of my time to do that.

Can you explain about the protocols?

The protocols that we've got in place are there for the active surgeries receiving all of the input from the research study. And they're there purely to set a standard, so that all the GPs that are in the active part of the research study are sticking to the same protocols, for the treatment changes for the people, for

lipids, for hypertension, and for glycaemic control, so that we can measure the outcome.

I've sensed, at times, a tone of frustration with your Asian patients: that they won't keep to the regimes suggested. Can you talk a bit more about that?

(14) It's hard work. There's a lot of myths and misconceptions, in the Asian community, about diabetes and other chronic diseases. And also, people tend to listen to other people. And unless you have an understanding of the population that you're dealing with, that can be a barrier towards whether they're gonna take on board what you want to. I, generally speaking, don't have a problem; everybody will listen to me. But sometimes, there are certain people that are stuck with their ideas and are not gonna change, either for religious reasons, or because an elder has told them different, or because of their own experience with relatives. So, you will get the few that decide they're not gonna do what you wanna tell 'em, whatever you're gonna tell 'em. And an example of this is things like herbal remedies. Some people will swear by a certain herbal remedy, or they'll say "my diabetes has gone away", or "I went to see a homeopath in Pakistan, and he gave me this, and my diabetes is cured, now". So, it's things like that which can inhibit whether a patient is going to take on board what you are going to tell them. And I think you, as a health professional, have to accept that there are gonna be certain people out there. And, until they're on that cycle of change - of acceptance - and they want to contemplate in making those changes, it's not gonna happen.

You mentioned misconceptions about diabetes and other diseases. What are common misconceptions?

Common misconceptions, such as: if you have too much sugar, that's what causes diabetes; if you've got sugar in your urine and nothing in your blood, you haven't got diabetes. There's many myths and misconceptions that Asian people have got, and you have to try and dispel those before you're actually gonna get them to take any advice on board, first.

(15) And you mentioned your own understanding of the culture being helpful. What kinds of cultural understandings do you have?

The influence of culture is really important on the way that people look upon disease, and also the generation. I mean, there's five to seven generations, now, in this country, of Asian people. And obviously, every generation has got a different view of how they're going to take on the disease on board. So, you have to cater your advice to suit that generation. For example, the younger Asian people in this country - most of them are educated - and they will be able to take on board what you're saying, read the literature, et cetera, whereas the older generation are very set in their ways, and they tend to take on board old advice, as such. So, you have to work a bit harder with those people. You have to give realistic advice to patients from different ethnic minority groups. I mean, for example, for Asian people, if I was to have a, say, sixty or seventy year old that

came through to me with diabetes, and they had a BMI of, say, thirty - which most of them do - you have to be very realistic as to how you're gonna give that advice. I mean, I wouldn't tell that lady to go to a gym, and do workouts five times a week, thirty minutes, because that lady is not going to go to the gym, first of all, because of cultural barriers. It's more realistic to say "you're going to need to go out for a walk, three or four times a week, maybe with your grandchildren in the evening". So, you need to pitch the advice realistically, with the right generation, with the right group of people, and with the right gender.

What gender differences would there be?

Certain groups... I mean, certain religions - for example, if you're a Muslim - there are certain women that will not go to, say, the gym, because there will be men there. So, therefore, you have to cater the advice, and also look around, in the area, to see if there are women-only sessions that they can go to. But also, the age difference as well. I mean, a sixty, seventy year old is not gonna wanna go to the gym, so you have to be realistic and see what you can cater or advise them to do in the home setting, or with the family.

What sort of things with the family or in the home setting?

Well, Asian people... I would say, most Asian people have DVD player or a video at home. And we love watching DVDs and Indian films, and films in general. So, it might be... I mean, you can, for example, say - I mean, also listening to Asian music - if they want to sort of do some form of exercise in the house while listening to Asian music. And also, there are some Bhangra dancing groups, exercise sessions, for women only that have started in our PCT (Primary Care Trust). So, I think PCTs are actually catering, now, for the population, 'cause they're realising, in order to get this advice across, and to get people to comply with treatment, they're gonna have to have ethnically friendly regimes in place.

(16) It's also very important that you educate health professionals about different cultures and religions, because, in order for them to give the advice, they have to be up to date. And also, it's probably beneficial for them to hear it from people that actually live and breathe it, or have had experience from it. And one of the things that I've done is hold Ramadan and Hajj workshops, at the hospital that I work in, for health professionals. And also how to cater the advice regarding insulin adjustment in certain times, such as religious festivals such as Ramadan. So, that's been useful, and we've had quite a good uptake from local groups, hospitals. And also nationally, we've had people that were interested, that have asked us about them, as well.

What kind of advice do you give for Ramadan and Hajj?

You have to cater the advice around... I mean, it's the advice you'd give to people that are diabetic normally, but you just have to cater it in accordance to... I mean, Ramadan is a fasting month, and therefore you have to cater

the advice around their eating pattern and regime for that day. Because, if they're on certain amounts of insulin, particularly, or oral hypoglycaemics such as sulphonureas, they do run the risk of hypoglycaemia. So, therefore, you do have to adjust the medication accordingly. So, the workshops that I run are mainly to do with that. And Hajj: Hajj is a pilgrimage to Mecca. So, therefore, there is a lot of exercise involved, and also, again, treatment regimes may have to be modified. So, that's one of the things that I do on the Hajj workshop: to familiarise health professionals on what they are, and how to advise people with treatment regimes.

And what kind of reactions do you get from other health professionals?

Really positive. They found it beneficial, and also interesting, because health professionals - and people in general - can have misconceptions about what certain religious festivals are. And it's purely because the information's not there; not because they're ignorant or they don't want to know.

We've mainly talked about Islam. Are there any cultural or religious considerations for Hindus or Sikhs?

Yeah. I mean, the main reason I've talked about Islam is because the majority of the people that I deal with, in my area, are actually from Islam and are Muslim. But we do get Hindus, we do get Sikhs. And, basically, you do have to cater for those people as well, and you have to look at what religious festivals they have, and what fasts they have. In each religion it's different, and, therefore, you have to cater the advice for that. And you have to have the literature for those people as well.

(17) You mentioned that there were five to seven generations here, now, from Asian countries. Would you like to talk me through the experiences of those generations?

Yeah. My Dad was probably one of the first generations to arrive here, and then my sisters are probably second to third generation. And then, I'm probably fourth generation, and then my nieces are probably fifth generation - she's about twenty five to thirty, my nieces; all of them are. And then, after that, they've had children. So, I mean, that's six generations, just in our house. I have seen a change in diabetes over the generations, in the sense that, when I started in 1995 as a DSN, the majority of Type 2 diabetes were in people that were, say, over the age of forty, on the whole. And you would get the odd few Asian people that were sort of between thirty five and forty. But what's happened is that, over the last... particularly the last five to ten years, the onset of diabetes is happening in younger people. And we're getting... it's very normal, now, to have an Asian person between the ages of thirty five and forty, if not younger - say twenty five plus - with Type 2 diabetes, and the problems associated with it. And we are getting people, now, from Asian backgrounds, as young as nine, ten, eleven, in the paediatric clinics. And I've heard of the paediatric diabetes specialist nurses saying that they have children as young as five, seven. So, the onset of diabetes is definitely becoming at a younger age, now. And also, I mean,

the generations, throughout the years... the way that my Dad, and what he ate, what was around to eat, the amount of fast food places - there were none at that time - so Dad had a proper cooked meal from home. As my sisters have had drummed into them, although they have the dabble of fast food here and there, they generally do eat at home. Whereas the younger generation, because there are so many fast food outlets, and because people, on the whole, are cooking less at home - and also people are losing the skills to do that and eat healthy - they are, generally speaking, eating more fast foods, because of time, whatever. I mean, fast food, in general, is very cheap, as well. So, we are seeing a very, very different dietary input from people from younger generations, and that goes for Asian, white, whatever. And that, obviously, is having an impact.

(18) So, from your experience of having three family members with diabetes, and working as a specialist nurse and a lead nurse in this study, what are your reflections about the disease?

My reflections are that diabetes has changed over the years. The approach to diabetes, from the health professionals, has changed, and the government. I think it realises that diabetes is causing the NHS a lot of cost, because of the complications associated. I believe it's something like 6 to 8% of the budget to the NHS is allocated to diabetes and related complications. I mean, that's a big amount of the budget. So, the government are putting a lot of money and effort into it: diagnosing it, treating it, et cetera. And people's attitudes towards it have changed - health professionals, in general - the way they approach the disease - it's not just a sugar disease. It's now looked at as a syndrome, whereby you have to look at things like lipids, hypertension, and glucose. So, I think the approach to diabetes is totally changing. And this was predicted about ten years ago, I remember, by the consultant that I worked for, and everybody thought it was really odd. And I remember going to a conference and listening to Sir Albertini, I think - I can't even remember his surname - but he's a very, very prominent figure. And he stood on the stage, and he said "there's going to come a time," I remember him saying, "that people will be suing people - fast food people - because of the complications that they are incurring from eating fast foods", and that they should have health choices in place so that they can have a choice to eat a healthy option and not just have take-away food. I remember him talking about traffic-signal colours on packaging, to tell you what was healthy, what wasn't: ie red, green and amber, so that people could make a choice of what was healthy and what wasn't healthy. And this has all happened, in the last five years. And the approach to diabetes and healthy eating has changed over the last five years. And this was predicted. I remember going to these conferences and listening to these people. George Albertini, I think that was the man. When I said George Albertini, I actually meant George Alberti. But very prominent figure, and I really, really did respect what he said at the time. And it's sort of like just dawning upon me now, as to what he said, then, has come true.